

PAPER TITLE:

'RESEARCHING THE DISCOURSES OF EMPOWERMENT AND SELF-HELP IN PEOPLE
DIAGNOSED WITH HIV ANTIBODIES: ANALYZING EXPERIENCES OF THE "HALLMARK"
OF AIDS (THE T-4-CELL COUNT).'

PRESENTED AT THE

BRITISH SOCIOLOGICAL ASSOCIATION ANNUAL CONFERENCE:

'MAKING SENSE OF THE BODY'

UNIVERSITY OF EDINBURGH, SCOTLAND, U.K.

APRIL 6-9TH, 1998.

AUTHOR: KEVIN P. CORBETT

Abstract

Gaining information and developing understanding about any medical condition is a central activity in self-help (Wann, 1995). Scant attention has been given to individual experiences of the technology deployed in AIDS care, as social science focuses more on gender and social policy issues with this syndrome. For example, individuals' "lived experience" of the clinical technology, such as the T-4-cell count, remain poorly understood. This paper draws on transcribed interviews with people diagnosed antibody positive, in order to analyze the knowledge and understanding of such technologies. Individuals' experiences of the "clinical reality" of AIDS (Treichler, 1992) may prove empowering but there is a dissonance with orthodox perceptions. When AIDS was initially identified, the T-4-cell count was proposed as measuring loss of immunity. This tool quickly evolved into a prognostic "test" for identifying the "hallmark" (defining characteristic) of AIDS: the reducing number of T-4-cells. Individuals report many "frames" of reference to contextualize their experiences of AIDS which contest such orthodox perceptions of the clinical reality. This self-help process parallels debates on "empowerment" both as a strategy for resistance against, or assimilation within, the dominant paradigms of thought (the "medical model" of AIDS). It is shown how discourses of people so diagnosed reveal that orthodox AIDS knowledges are representative of a science which is "dialectical/**undetermined/underdetermined**" (Fujimura and Chou, 1992).

INTRODUCTION AND BACKGROUND

"AIDS..an immuno-deficiency disease, which was after all, how it was first recognized and how it got its name; while we now also perceive it as part of the spectrum of an infectious disease, it is still crucial to examine it biologically and diagnostically from an immunological perspective..on the principle that most of what we know and need to know about the disease will be 'told' us by the patients, if we listen carefully.."

Pinching (1986 p.36)

"The term *AIDS discourse* is not simply descriptive but entails an examination of the context - the entire apparatus - through which utterances about AIDS are produced and interpreted and speaking positions are made possible."

Treichler (1992a p.88 emphasis in original)

"What should be said of the laboratory findings as an aid to diagnosis ? It has been said, perhaps with more truth than elegance, that doctors go to the bedside of the patient "stinking of the laboratory." Yet all know that laboratory research has done more in recent years to elevate the standard and broaden the influence of the medical profession than all other branches of medicine. In practice, however, laboratory reports may be of little or no real diagnostic value; worse still, they may be very misleading.."

Kimberlin (1912 p.271)

I am a nurse and once worked with in a hospice where individuals with AIDS-related illnesses came to convalesce. One patient, Tony, often talked about the meaning of his T cell (CD4+) count and the tumor which his HIV specialist had diagnosed in Tony's chest. The specialist said Tony had 'AIDS' because the tumor looked like a specific Lymphoma. Tony challenged this diagnostic label, saying his CD4+ count was too

high and he had no symptoms. Tony said the tumor was an artefact, something found by looking 'too closely', and that his CD4+ count was too high for him to have an 'AIDS diagnosis'. Tony was questioning the clinical significance of his blood serum being judged positive on the ELISA testⁱ. I asked Tony how he understood the separation of the two diagnoses which the specialist saw as causally related ? Tony thought he may be one of the many who develop Lymphoma irrespective of their positive ELISAs. He thought the Lymphoma and the presence in his blood of antibody reactive on the ELISA were not causally related.

I understood that Tony's knowledge and experience enabled him to de-construct his understanding of the accepted, or 'orthodox', view of AIDS. Tony's acquisition of information and development of personal knowledge and understanding of the technology used in his diagnosis appeared central to his process of self-help or empowerment (Wann 1995 p.ii). This process may mediate the perceptions of a particular medical condition and so enable or 'empower' the individual.

Mediating structuresⁱⁱ have evolved in AIDS care from self-help initiativesⁱⁱⁱ and are all representative to a greater or lesser degree of both the range of belief about the causation of AIDS and also the differing experiences of individuals and 'at-risk' groups. They offer different frames of reference within which the individual can become personally empowered and so comprise an "arena of discourse regulation" which mediate and/or consolidate individual experience,

either within the discursive frame of orthodox "AIDS thought styles" (Horton & Aggleton, 1988 p.96) based upon 'germ theory' (the 'medical model of AIDS')^{iv} or within other discursive frames, such as Tony's, which necessitate a deconstruction/reconstruction of orthodox AIDS science and the meaning of the ELISA test^v. This paper's position is similar to that of Horton & Aggleton (1993) who argue that the AIDS research paradigm is a "post-hoc rationalization" because of the chronological isolation of HIV after the emergence of clinical AIDS. They further state that: "Following Feyerabend's (1975) critique of the history and practice of science, we should be wary of post-hoc rationalizations such as these. HIV was not isolated and identified until long after AIDS had first been diagnosed. The effects of scientific histories of this kind are many and varied, but we should recognize that in this case at least, one result has been to squeeze out from the open arena of debate, alternative accounts of AIDS" which are: "competing or complementary modes of explanations of the syndrome" (Horton and Aggleton, 1989; 76). Within this scenario of the "consensus view" they state that there are many "contestable issues" such as the: "characterization of AIDS as a sexually transmitted disease, rather than as a blood borne viral disease" (Horton and Aggleton, 1989; 76) as the Hepatitis B model prefigured AIDS and upon which the epidemiology of HIV was founded. It is interesting to contrast their 'consensus view' with that of the AIDS 'orthodoxy', defined by a long-term survivors magazine as:

"The orthodox view on AIDS holds that it is caused by a

virus known as HIV that is transmitted through the exchange of bodily fluids. Once infected, a person will remain well for a time, though infectious to others, before going on to develop AIDS and dying. Despite the huge sums of money spent on medical research, there is still no cure, just drug therapies said to slow the progress of the disease, and regular T-cell counts to measure health. A whole industry has evolved around AIDS, on which many careers and businesses depend, but which offers little hope to those affected. It works on the premise that HIV=AIDS=DEATH" (Continuum 1997 p.1).

This paper utilizes the discourses of individuals judged positive on ELISA screening in order to focus on the central tenet of the AIDS orthodoxy^{vi} ('medical model of AIDS'), the declining number of T cells. Important milestones in the 'AIDS patient-experience' as 'lived experience' or "the way people encounter situations in terms of their own personal concerns, background meanings, temporality, habitual, cultural bodies, emotions, and reflective thoughts." (Benner, 1989; 410) remain poorly understood. For example, such experiences of the AIDS 'technics'^{vii} like the T-4-cell count. In 'clinical AIDS' the reduction in the number of a patients' T cells has always been considered due to HIV-mediated T-cell death, an assertion now refuted (Rosenberg *et al.* 1998, Wolthers *et al.* 1998, Papadopoulos-Eleopoulos 1998, 1997, 1996, 1995, 1993a, 1993b, 1992, 1988, 1982) thus leaving a hole in the retroviral causation theory of AIDS, the 'HIV-AIDS hypothesis' and further problematizing experiences of AIDS screening/testing technology.

This paper aims to further understanding of such 'clinical' experiences in AIDS and to reflect upon its clinical utilization and application,

as arising within individuals' discourses on the count, for example, Tony's. The paper focuses on the prevailing discourses on the T cell count using data from in-depth interviews with those judged positive on ELISA screening. This exploration^{viii} of individuals' understandings and meanings in discourse engendered by the widespread clinical utilization of the T cell count aims to inform our understanding of such technics in AIDS especially understanding of what is problematic and controversial in clinical AIDS as suggested by the reverse/counter discourse of Tony and the self-help groups resisting ELISA screening and the AIDS orthodoxy, where 'reverse discourse' is defined following Foucault as that: "...which speaks in its own behalf, to demand its legitimacy or "naturalness" (to) be acknowledged, often in the same vocabulary and using the same categories by which it was medically disqualified" (Foucault 1976 trans. 1978; 101). Thus, specific concerns relating to the science underpinning the test will be addressed as they arise from individuals' discourse. The latter will be utilized to further explore issues pertaining to the ethical use of such technology in health care.

The working assumption of this paper is that T-cell counting may be problematic for all, patients and health care workers alike. Following Lipman (1994), in no way does this paper intend to reflect negatively on those who have considered or have undergone T-cell counting with the orthodox belief or otherwise that they are infected with a retroviral agent. Thus, criticism of the technology is not criticism of the

individuals so screened.

The T-4-cell count

The immune system is thought to utilize specific white blood cells, termed 'T' cell lymphocytes^{ix}, to orchestrate the death of pathogens^x. Before identification of HIV, the measurement of ratios of the types of T-lymphocytes (Morbidity and Mortality Weekly Review, MMWR 1982, Sonnanbend 1983, Sonnanbend & Saadoun 1984) and their "absolute numbers" (MMWR 1981 p.1) revealed altered numbers of such cells. Thus, it was thought AIDS patients had significantly altered numbers of these white blood cells (Detels *et al.* 1983, Pinching *et al.* 1983)^{xi}.

Following such reports, AIDS patients became characterized by their altered ratios of subclasses of T cells (the 'T-4:T-8 ratio') and by their declining number of one specific subclass of these blood cells, the T-4 'helper' cell ('T-4-cell'). Hence, this contiguous/co-occurrence of declining T-4/CD4+ cells in AIDS patients led this noted reduction to become a metonymic signifier for the cause AIDS^{xii}. Also, the orthodoxy ('AIDS is an immunological disorder of retroviral causation') came to perceive the T-4-cell count as a biological marker of probable "disease progression" (Oppenheimer 1988 p.289) and thus an "independent predictor" for developing AIDS (Polk *et al.* 1987 p.61)^{xiii}. Hence, this resemblance/replaceability for the decline in numbers of T-4 cells for the syndrome itself, led it to become a metaphoric signifier for AIDS. For example, the orthodoxy

considers the decline in the T-4 cells as the "hallmark of AIDS" (Sande & Volberding 1990 p.186, Levacher *et al.* 1992 p.380) and "one of the main features" (Wolthers *et al.* 1998) of retroviral causation^{xiv}.

The T-4 cell count was used in one of the first staging systems for AIDS, the Walter Reed Staging Classification (Redfield *et al.* 1986). Partly due to AIDS activists, the T-cell count was further institutionalized through its inclusion in case diagnosis (Centre for Disease Control, CDC, 1992)^{xv} and further utilization in prognostic screening and clinical practice (Horton 1989). However, it was already deployed in the clinical evaluation of therapy (Gulick 1997, Hammer *et al.* 1997, Hamilton *et al.* 1992, Dournon *et al.* 1988) and for structuring standards of care (Philadelphia ACT UP 1992).

The T cell count, like its companion diagnostic, the ELISA screen, is clinically and ethically controversial. The decline in the number of T-4-helper cells (T-4 or CD4+ count), deemed so characteristic of AIDS, is "...still not completely understood" (Wolthers *et al.* 1998 p.44). The presumed HIV-mediated T-cell death at the centre of the AIDS orthodoxy was refuted as early as 1986 by Luc Montagnier, 'discoverer of the AIDS virus'^{xvi}, (Klatzmann & Montagnier 1986) and more recently by others (Rosenberg *et al.* 1998, Wolthers *et al.* 1998, Papadopoulos-Eleopoulos *et al.* 1995). Its clinical deployment and utilization as a reliable diagnostic/prognostic tool is ethically dubious given the enormity of this current doubt about: "...the value

of using changes over time in CD4 count as a predictive measure for effects of antiviral therapy on disease progression and survival" (Concorde Study Interim Report) (Aboulker & Swart 1993 p.889). However, the T cell counting currently is a daily reality for individuals so diagnosed (Blacklock 1997, Body Positive 1996). People are encouraged to believe it as valid and reliable for decision-making and further screening (Body Positive 1996). Also, these assumptions are implicit within pharmaceutical texts in advertisements targeted at the gay/bisexual men, for example, the February 1997 advertisement from Roche Products Limited (Positive Nation 1997 p.35).

THEORETICAL FRAMEWORK

The conceptual perspective for this examination uses upon Hanson's critique of the authority of testing for conceptualizing the T cell count as a 'test' (Hanson 1993). Also, Rosenberg (Rosenberg 1992) and Harrington's (Harrington 1996) postrelativist perspective on disease/illness (Rosenberg 1992, Harrington 1996) is discussed for its value in understanding the 'natural' phenomena of the T-cell count.

Measuring and testing

Given the fact of current medical screening technology several characteristics of the T-cell count epitomize Hanson's analysis of the distinctive features of 'tests'^{xvii}. Firstly, such technology purports to 'objectively' measure, yet actually does more than just simply measure. For example, by 1977 and pre-AIDS, studies of the immune system indicated T cells had 'suppressor' and 'helper' activities thought to be separate functions of distinct subclasses of T cells, differentiated by a variety of cell-surface proteins ('markers') thought to be specific to each subclass (Cantor & Boyce 1977). Hence, the simple measurement of numbers of T cells in itself made possible the utilization of such measurement for the screening of these already-occurring phenomena, the number and types of T cells. Thus, such 'simple' measurement became useful for assessing incidence and prevalence of poor immune function ('immunocompetence').

Secondly, 'tests' are intentional and are planned with "some purpose

in mind" (Hanson 1993 p.16). Hence, already-occurring conditions, such as the body's levels of T cells, become tests when actively employed for "the purpose of acquiring knowledge" (Hanson 1993 p.17). In this case, acquiring knowledge about incidence and prevalence of immunocompetence. Thirdly, to constitute a test, a difference is needed between the 'test result' (the 'facts' directly collected) and the 'target information' (the point or purpose of the inquiry) (Hanson 1993). For example, pre-AIDS the 'target information' of the T cell count was the measurement of immune function by measuring T cell subsets (the point or purpose of the inquiry). Post-AIDS, this target information shifted to the detection of immune-deficiency in "at-risk" individuals or populations, assessment of their likelihood of developing AIDS-related opportunistic infection ('OI's') and the construction of a model for AIDS progression and the institution of drug prophylaxis against the potential OIs (CDC 1992, Philadelphia Act Up 1992)^{xviii}.

Therefore, the T-4/CD4+ cell count is a test based upon a representation which distinguishes between the signifier (the test result - the numbers of T-4/CD4+ cells) and the signified (the target information - immunocompetence, risk of developing OI, need to prophylax). In this test the signifier and signified are related through metaphor (relation of resemblance or replaceability) and metonymy (relation of contiguity or co-occurrence) (Hanson 1993). Following on from the above, a low T-4/CD4+ count is a metaphoric signifier for AIDS because it resembles/characterizes the declining T cell counts first noticed

in AIDS patients. Furthermore, it is a metonymic signifier of the hypothesized 'causative agent' in AIDS in several ways. Firstly, declining T-4/CD4+ cells were a contiguous/co-occurrence in the first AIDS patients in the absence of ELISA screening. Secondly, post-1984, the low counts in 'at-risk' groups also became a metonymic signifier for AIDS, defined by a potential positive result on ELISA screening, and thus a metonymic signifier also for the presence of antibodies to the human immunodeficiency virus.

Empowerment and the self

This paper views self-help and empowerment as concepts and processes which exist within a dialectical relationship to professional help. As concepts, they have the potential to facilitate a "psychologically-focused diversion" away from "societal criticism and cultural change" (Reissman 1990a p.44). As rhetorical processes, they may facilitate the re-structuring of help where the helpee, the recipient or consumer of help, becomes its producer or 'prosumer' (Reissman 1990b). Thus, empowerment/self-help can potentially re-position the subject in relation to institutionalized authority so that the object of help, the recipient or consumer of help, becomes part of the solution, the subject or agency of help^{xix}. Likewise, the process self-help/empowerment, within the context of AIDS, may enable a re-positioning of the individual so diagnosed, the object of help, to become the subject or agency of self-help. Thus, individuals' discourses on the T cell count may be analyzed by focusing upon the

speaking positions assumed and the stances formed within such discourse as suggestive/representative of such re-positioning either in relation to the orthodoxy or otherwise, such as in the example of Tony.

Frames of reference

Rosenberg describes AIDS as underlining the need to 'factor-in' bio-pathological mechanisms to understand the social negotiations which 'frame' diseases (Rosenberg 1992). Harrington develops this argument by describing how science does not simply 'mirror' the realities of nature 'objectively', but engages phenomenal realities "...which 'talk-back' in ways richly generative of human meanings and social imperatives" (Harrington 1996 p.xxiii). Hence, what is considered as the 'natural' may be "brought inside human history and enabled to play a role in any number of human dramas.. without neglecting the role, so self-evident to scientists, played by the non-human, the material and the unexpected.." (Harrington 1996 p.xxiii) which may pose as "...solutions to the cultural imperatives of the time" (Harrington 1996 p.xxiv). Thus, medical technics like the T cell count may be conceptualized as engaging the reality of the immune system to construct a "pre- or proto-disease state" (Rosenberg 1992 p.xxv) which describes/measures so-called altered immunity by the T-4-cell count in order to solve a variety of cultural imperatives.

METHODS

The experience with Tony indicated that the analysis of spoken language would be a useful means for understanding empowerment in AIDS; not so much in the 'formal' or linguistic sense, but more in the political way speech may be deployed or utilized in *discourse*, where:

"..'discourse' is used to refer to primarily language..

'Discourse' is used instead of 'language' because discourse connotes the actively political and strategic role of words and how they are connected to form sentences and construct meaning. This differs from understandings of 'language' that imply universal and fixed linguistic structures and meanings for words. An analysis of discourse is concerned with discovering how and why and under what conditions words and phrases have specific meanings and what can be learnt about the politics underpinning the structuring of a particular discourse at a given historical moment."

Grace 1991 (p.330)

This paper is based on interviews with individuals judged positive on ELISA screening/diagnosed with AIDS. The paper uses relevant sections of transcribed interviews from a larger study of 'empowerment' and self-help in AIDS. Individuals were recruited from a range of health and community-based services ('mediating structures') through advertising and 'snowballing'. Twenty-four in-depth one-to-one tape-recorded interviews generated discourses on self-help and empowerment. The approach to discourse analysis identifies, documents and explores discourses in order to develop understanding about how and why meanings arise and how they are interrelated.

This method stems from Foucault's (Foucault 1966 translated 1972,

1969 translated 1972) concept of discursive fields whereby existing discourses compete for prominence (Foucault says 'dominance') in order to define and thus structure individuals' social reality. This paper views all research in AIDS as positioned within fields of competing discourses, whether consciously acknowledged or not. This includes competing discourses on personal experience such as self-help and empowerment, which given the medicalized nature of AIDS often entwine with competing discourses on causation, such as Tony's. In context of the 'cultural fault lines' (Schmidt 1984 p.) in AIDS, its medicalized discourses entwine with competing discourses on gay rights, treatment activism (Epstein 1997) and associated interpretations of virology (King 1997) to name but a few.

The analysis focuses on self-help/empowering discourses which are, themselves, generated from within institutional ('medicine' 'biomedicine') and mediating structures ('mediating structures'). The above mediating structures are representative to a greater or lesser degree of both the range of beliefs about AIDS causation ('orthodox'/'dissidence') and the differing experiences of individuals and 'at-risk' groups. Thus, individuals' recruited from within these mediating structures will reflect the discourses which circulate within the mediating structures in attempts to define and give meaning, so structuring and/or constructing, individuals' social reality.^{xx} For example, references in the transcribed interviews to the CD4+ T-lymphocyte (cell) count often utilize an immunological frame to

speak of the differing "personal and policy decisions" (Rosenberg 1992 p.xxv)^{xxi} faced by the incorporation of such technics, perceived or assumed as 'natural' or 'out-there', into everyday life. Also, this examination is in context of the aforementioned critique of empowerment which can act as 'positioning' process for the speaker across a spectrum of speaking positions within and/or against the orthodoxy, as previously defined. In this study, it is acknowledged that the researcher cannot be neutral as they actively participate in the social process of the interview, but are perceived as so doing within a reflexive understanding of their current/historical position and in relation to the existing discursive fields in health care practice (Corbett 1997a).

Therefore, a more fertile and grounded analysis needs to address what Macdonnell calls "the politics of meaning" (Macdonnell 1986 p.45) where words change their meaning from one discourse to another, and "conflicting discourses develop even where there is supposedly common language" (Macdonnell 1986 p.45). Such analysis may be more powerful for developing understanding from a basis of 'praxis' or experience 'grounded' in AIDS care/treatment (Corbett 1997a 1997b)^{xxii} where, for example, the 'meaning' of the 'CD4+ T-cell count' may differ between discourses, as such meanings form "part of the 'ideological sphere' and discourse is one of ideology's specific forms" (Macdonnell 1986 p.45). Therefore, in this examination of the CD4+/T-cell count, meaning is conceptualized as existing "...antagonistically: it comes from

positions in struggle" (Macdonell 1986 p.47) and thus, it is argued that "words...change their meaning according to the positions' from which they are used" (Pêcheux 1975 translated 1982 p. 111 cited in Macdonnell 1986 p.47). Thus, in this paper on the T cell count it is really that which creates different speaking positions and the processes which operate during the taking up or adoption of such positions which are being analyzed.

DISCOURSES ON THE CD4+ T-CELL LYMPHOCYTE COUNT

"..Oh by the way..the results are back.."

The T-4-cell count is measured by a laboratory process called flow cytometry. First, a sample of blood taken from a person's vein is needed, usually from the individual's arm:

"..you go every three months or so (to the clinic) and they draw the blood..for every CD4 count you get the results when you go back for your next appointment..it happens sometimes I've thought oh I don't know what this is.. let me go and check have it checked and while I'm there..the doctor says "Oh by the way..the results are back"..they do come back now every 2 days.."Oh have you had your CD4 results from the last lot".."

(ALAN)

Thus, analysis of the sample occurs away from the clinic in the laboratory.

In this scenario there is an invitation and option to know, or not know, the results:

"Well..first of all he (the doctor) asked me did I want to know it..which I its not imposed on me in that respect..first of all I have the choice of finding out or not ..and OK as of late I've taken the choice..I've taken that option.."

In relation to the distinctive features constituting a 'test', the count is used for the purpose of acquiring knowledge; not the already-occurring knowledge of the ratios of types and absolute numbers of T-4 cells, but knowledge about the individual's degree of compromised immunity ('immunocompetence'). At the beginning of AIDS 'cohorts'^{xxiii} of individuals were screened. The T cell counts were correlated with diseases for the purpose of producing averages for the cohorts (CDC 1982, MMWR 1997, Hoover *et al.* 1992)^{xxiv} thus, establishing the utility of this technic:

"If your CD4 count is persistently below 500, your immune system is slightly weakened and you are at gradually increasing risk of infections the further it falls. if it drops below 200 you are at increased risk from serious infections. At this point your doctor should offer drugs to try and prevent such infections, such as co-trimoxazole for PCP pneumonia. Likewise, if you CD4 count starts to drop rapidly or falls below a certain point, or you develop symptoms, you may be advised to consider taking anti-HIV drugs."

Body Positive Newsletter (1996 p.4)

"..what is the value of these counts ?.."

The trend in the T cell count is a frame for conceptualizing and/or referring to 'progression'. In this framework diseases and T cell count are positioned in an opposing dynamic of disease incidence versus declining T cells. This construction contextualizes prognosis and diagnosis in AIDS through 'staging' the immunodeficiency according to declining numbers of T cells. Thus, the 'clinical value' of the technic is revealed:

"..and I did manage to say to (the doctor) one day "Come on level with me what is the value of these counts.." and he said "We only use it over a long range..we look at it over say an 18 month period and see what changes have gone on in those 18 months.. is it going down slowly ? is it staying the same ? is going up ? you know.."

JOHN

Hence, the clinical value of the T cell count emerges over successive recording of absolute values and the construction of a trend over a "long range". Yet other values are expressed such as not wanting to know whilst one is well and apportioning the responsibility for judging the value of the information back to the physician:

Interviewer:"Do you have your CD4+ count measured regularly ?"

JAMES:".. the T cell count.. ? It was two hundred at one point and then it went up to two forty I don't tend to ask about it I rely on the Consultant

to give whatever information he thinks is necessary
for me I'm not one of these people ..who wants
know their T cell counts every week ..

..if I'm feeling fine I'm not bothered about it..that's
how I look at it..

You know I could just sort of gone on maybe had two cells
T cells whatever you.. and it doesn't bother me
I don't to particularly know unless he wants to
tell me ... you know I had to know for my benefits
and things because they had to know 'cos I have
to be signed off sick that was the only time I've
ever known and I was two forty last time and I
could be five forty now I don't care I feel wonderful
so if it's two or four five hundred it makes no
odds makes no odds to me at all..

Main thing is I'm well and I feel well and I feel I can
go back and play tennis again and I couldn't walk
four months ago I was completely paralysed down
one side.."

*"..I'm a little bit unclear myself whether I've technically got an
AIDS diagnosis.."*

Uncertainty is experienced over how the "technical" construction of
the AIDS diagnosis is applied to the individual^{xxv} or which rules are
being followed:

"I'm a little bit unclear myself whether I've technically
got an AIDS diagnosis it depends which rules you follow
although I've not had one of these indicative infections
but obviously a very low T cell count suggests that there's
something specific happening..although to some extent it's
the luck of the draw which of the opportunistic infections
and when I shall be affected.."

JOHN

The 'rules' are those of subjective clinical evidence (what the patient
says, what the physician observes) or those of "technological evidence"

(Reiser 1978 p.230) like the T cell count ? Thus, the 'biological'/laboratory diagnosis of AIDS was historically (re-) defined:

"Acquired Immunodeficiency Syndrome
(AIDS)
(Effective January 1, 1993)

Case definition

CDC has expanded the acquired immunodeficiency syndrome (AIDS) surveillance definition to include all human immunodeficiency virus (HIV)-infected adolescents and adults aged greater than or equal to 13 years who have **either** a) **less than 200 CD4+ T-lymphocytes/uL**; b) a CD4+ T-lymphocyte percentage of total lymphocytes of less than 14%; **or** c) any of the following three clinical conditions: pulmonary tuberculosis, recurrent pneumonia, or invasive cervical cancer. The expanded definition retains the 23 clinical conditions in the AIDS surveillance case definition published in 1987...

CDC has revised the classification system for HIV infection to emphasize the clinical importance of the CD4+ T-lymphocyte count in the categorization of HIV-related clinical conditions. This classification replaces the system published by CDC in 1986..."

Center for Disease Control (1992)

In this biological diagnosis of AIDS, T cells in the body are perceived through the screen of technology which necessitates the relinquishment of control over the very diagnostic/prognostic processes through utilization of the machinery and specialists of laboratory-based technics. Thus, the most authoritative rules governing AIDS diagnosis are the CDC surveillance case re-definition premised on T cell counting where clinical diagnosis becomes secondary to laboratory/biological diagnosis (CDC 1992)^{xxvi}. Papadopolus-Eleopulos *et al.* (1995) describe

how the recent CDC definition of AIDS problematizes the empirical construction of AIDS by redefining the syndrome using just two types of evidence: serological (positive ELISA screen) and immunological (T4 cell count $< 200 \times 10^6/L$). The establishment of a trend through on-going surveillance ("is it going down slowly ? is it staying the same ? is going up") constructs and constitutes the biological diagnostic/prognostic of AIDS^{xxvii}.

"..you have this enormous burden of a knowledge loaded on you.."

Yet, occurrence of any one of the specified number of the OI indicative of AIDS in the CDC criteria is uncertain. The correlation of falling T cell count and opportunistic illness is more than a measure of immunocompetence; it is both a diagnostic frame of assumed immunocompetence amongst 'at-risk' individuals, and a prognostic frame which announces OIs without any certainty over their occurrence or their character. Thus, by the same token that the laboratory provides a characteristic immunological 'profile' or context for the immune-deficiency of AIDS, likewise the normative diagnostic/prognostic frame of the T cell count provides an 'objective' measure or context for individuals' experience of vague symptoms, in further context of a judgement on a positive ELISA screen. For example, with reference to the range of symptoms experienced:

"..and sometimes tiredness and fatigue..but then it's very difficult to put these in a context because you know I am not the energetic person I was ten years ago and that's

maybe as much as to do with the fact that I am ten years older as anything else in a way it's part of the problem with HIV is that its very difficult to grasp, because you have this enormous burden of a knowledge loaded on you about an underlying medical condition (and) until there's something specific and real to react to it's quite difficult to get a purchase on it and I suppose one objective measure is something like declining T cells.."

(DAVID)

"..When my T cells went down to 50 last year that was as I said a shock.."

Therefore, the so-called 'objective measure' of "declining T cells" becomes a normative frame for understanding bodily changes within this protodisease state, the "underlying medical condition". The decline in numbers of T cells become something "specific and real to react to"; it shapes the experience and the progression in this protodisease state and thus is instrumental in affecting a lifestyle within this state. The experience of the order and severity of the symptoms are further underlined with reference to this 'objective' frame:

"..it's just that the infections are more resistant and harder to get rid of.. skin things rashes recurrent herpes attacks which appear to become increasingly virulent rather than less which is the normal progression, I suppose if anything it could be summed up in the phrase don't wait for tomorrow.."

I think because I've known I've been HIV positive for such a long time as time goes by it becomes a slightly unreal piece of knowledge..nothing appears to be changing other than the minor things I've referred to and I think we all have a sense of or are able to get a sense of mortality

whatever our condition and we think we are going to be here forever though intellectually we know we are not and when my T cells went down to 50 last year that was as I said a shock because whatever the arguments about what they actually mean there's something very objective about that I felt a need to react to .. and I have had to think what do I want to do with my life in the period of good health that I had left."

DAVID

Despite the "arguments over meaning", the lowered count is experienced as "a shock"; it symbolizes a poor prognosis within the orthodoxy and necessitates thinking about how to spend the future period of good health left, thus implying the latter is limited. Thus knowledge of a falling count facilitates the anticipation of worsening health, which the orthodoxy assumes reflects the degree of HIV-mediated T-cell death. Yet, the very invisibility of what is being measured has a psychological impact:

"..but again these (T cells) are sort of invisible things in your body whilst..it's obviously nice to have a lot of but..it doesn't really affect my experience of life..but in a dramatic way knowing that I've got fewer T cells than I had 2 years ago has a kind of psychological effect and in the last couple of counts which have been extremely low were a shock...I think they made me reassess what I am doing with my life in a way that surprises me really. But it's all rather vague things. There's nothing really specific and objective that I can grasp about it.."

JAMES

The T cell count appears not exert any 'real' or material effect on the experience of life until knowledge-gain about a downward trend. Thus, the count is experienced as exerting a "kind of psychological effect" in context of uncertainty about its essential meaning. Its

power lies in the symbolism of the downward trend/low count, described as "a shock". The orthodox meaning of the T cell count is suddenly framed for the self, that is a downward count implies one needs to reassess the remaining life left which presumes there is not much left.

The description of "a shock" and the invoking of anticipatory thinking about illness and its implication of death is illustrative of the T cell count as a metonymic signifier for AIDS progression, a form of psychogenic trauma^{xxviii}. Young describes the origin of psychogenic trauma,^{xxix} thought of as the power of experience to cause intense emotion, pain and disease. Historically the universality of the body and physical pain became genealogically connected indirectly to the mind, so providing authoritative discourses on traumatic mental suffering for both medicine and science. This connection was mediated through the discovery/invention of the 'traumatic memory'. Young pinpoints the critical moment of this genealogy in the development of understanding about recurrent trauma and its role in producing not a "summation", where the physical effects of multiple exposures accumulate and lead to the progressive destabilization associated with voodoo death^{xxx}, but a "transformation", where during periods of exposure to traumatic shock/trauma, the organism returns to homeostasis, but "a state different from the *statis quo ante*" (Young 1996a p.245-260).^{xxxi}

The similarities of the latter process with T cell counting center

of the common experience of shock described in the above discourse and other reports about the experience of 'test' results in AIDS^{xxxii}

Firstly, the discourse on the T cell count describes the experience of receiving the count as "...a shock." causing one to "reassess" remaining life in anticipation of poor health, thus resonating with Young's descriptions and explanations for psychogenic shock, and in context of the inherent prognostic fatalism already embodied within the orthodoxy about the T cell count^{xxxiii}. Secondly, the experience of receiving a count is a regular occurrence, given the operation of the cohort system. Therefore, in context of Young's analysis, there may be a recursive, accumulative or dialectical effect from the emotional experience of receiving the test result. In this way the T cell count cannot be considered as a 'static' decontextualized event, but one which implies dire "consequences for the future" as it evokes emotional responses in the individual which necessitate one to "reflect upon the past" (Rosenberg 1992 p. xix) as well as the future.

Thirdly, as reference is made to "shock" as a psychological experience there remains the question about the nature of the power endowed within the event which causes the individual to reassess or experience "a shock". The T cell count appears to be endowed with power in an embodied or codified form which over-determines decline/terminality or 'progression' to AIDS. Although, the cultural ramifications, contexts and universal biological mechanisms of Cannon's description of voodoo

death are historically transformed in Young's analysis, there are similarities given the power embodied within this technic^{xxxiv} which moves an individual into action or agency ("reassessment") based upon recognition of, or belief in, the embodied/codified/implied meaning of the falling T cell count, that is declining wellness and death.

"..Once you have a T cell count of below what was it 200 250 you have an AIDS diagnosis..

Therefore, there appears to be an imperative or compelling characteristic of the count, which may lessen the likelihood of refusal to know the count once a regular pattern of clinic attendance is established. The diagnostic meaning and that which it constitutes ('AIDS') lies embodied within the technic and is thus revealed^{xxxv}:

"..and I'd leave the clinic ..worrying oh God..300 is that good is that.. is 300 any good what does the CDC (Center for Disease Control) say ? ..the last I'd read something you remember at one point the CDC said that irrespective of whether you were symptomatic or not..once you have a T cell count of below what was it 200 250 you have an AIDS diagnosis well that was a big step you know.."

ALAN

The orthodoxy views a T-4 cell count of less than 200mm^3 as diagnostic of AIDS, in the absence of any clinical disease (CDC 1992). Thus, at the point of 200mm^3 the T cell count "technically" benchmarks a further shift within this normative frame of faltering immunity. This point is representative of the potential onset of OIs, thus it is

the point for prophylaxis to insure against the (unknown) probability of illness:

"..when my count went down..in the last 8 months I started prophylaxis for PCP (Pneumocystis carinii pneumonia) and I take Acyclovir as well..I had varying experience with the PCP prophylaxis Septrin...it seemed to be fine for nigh on 6 months and then I broke out in a hot rash... then I went into Dapsone which made me feel bloody awful so I stopped that one for 2 weeks

JOHN

The point at which the T cell count provides a benchmark for prophylaxis is the point at which the 'test result', the count's simple measure of T cells, most noticeably differs from the count's 'target information', the point or purpose of its inquiry. Thus, the relationship between the signifier (test result) and the signified (target information) shifts dramatically from that of a metaphoric signifier for immunocompetence to that of a metonymic signifier for "gradually increasing risk of illness" at 500 mm^3 and for "serious illness" at 200 mm^3 (Body Positive 1996 p.4). At 200 mm^3 the T cell count becomes not only a calculated method of acquiring knowledge about the individual's immunocompetence, their likelihood of developing AIDS-related illness and a means for constructing a normative scale for illness-probability in anticipation of OIs, but also the point at which the value of the count becomes instrumental for initiating prophylaxis against the presumed certainty of an uncertain illness. In addition, the technic overlays a normative scale upon the experience of the self within this protodisease state which is underwritten by a positive ELISA screen. As with all such overdetermined frameworks,

there is an implicit beginning and an definite end. Essentially it is finite:

"One thing I've been aware of in last 12 months is a kind of..I feel my life and my plans for the future are taking place within an increasingly shrinking space and it's I think in a way I'm trying to counteract that because the normal experience of mine is you have a sort of open ended expanse in which to plan all kinds of things... but my aim really is to try and..its rushing around trying to fit everything in..though when I'm feeling bad that's maybe how I feel about it..it's about optimising things... "

JOHN

'..the reason I was not interested in CD4 counts was from what I'd read professionally..'

For cohorts of those judged positive on ELISA screening the offer to routinely undergo further medical screening has been a familiar and commonly accepted invitation since the emergence of AIDS, similar to Kenen's account of the "diagnostic invitation" and the "gift of knowing" (Kenen 1996 p.1546). Starting one's 'patient-career' means accepting the invitation to attend for blood tests, including the

T cell count:

"..to begin with yes because everybody thought it was important ... but my CD count has been below twenty for about the last three years I don't even ask what it is anymore..it's probably in minus figures now and I just realised the reason I was not interested in CD4 counts was from what I'd read professionally and also that the people who'd had CD4s of four hundred had dropped dead and people

who had CD4s of twenty and didn't even have an AIDS diagnosis..I mean one of my friends who was diagnosed in 1983 and he hasn't got an AIDS diagnosis yet

DAVID 1997, Specialist Nurse for HIV & AIDS

Therefore, the count can be perceived of as redundant when its embodied meaning ('progression', 'immune-deficiency') does not accord with accrued personal, professional and social experience. Such frames of reference may be 'personal' if one personally survives three years with counts below 20 mm^3 and 'social' when one experiences friends surviving with few T cells whilst others die with higher counts. It is also 'professional' when one reads immunology journal-science refuting HIV-mediated T cell-death and the central role of the T-4 cell in the orthodoxy:

"Certain basic aspects have to be considered when the number of CD4 cells and the CD4/CD8 ratios in the blood are taken as indicators of the disease state of an infected patient. For example the mean CD4/CD8 ratio increases with age from 1.9 ± 0.7 in 20-30 year old females to 2.79 ± 1.18 in over 60-year-old females. **Furthermore, blood CD4/CD8 ratios differ between males and females, are under genetic control in humans and vary according to antigenic history** (challenge by non-self antigens/infections in your lifetime).

Indeed a blood sample can be viewed as a diagnostic window of the whole lymphoid system only when kinetic data and the subset composition in all organs are known.

Clearly the change in CD4/CD8 ratio and immune function is multifactorial and cannot be explained solely by a model of CD4+ cell destruction by virus.

Notwithstanding the changes in lymphocyte numbers and subsets in blood, loss of structural integrity of lymphoid organs and loss of immunological competence are clearly the important predisposing factors that determine the onset of AIDS.

Rosenberg et al (1998 p. 10-20 emphasis added)

Thus 'professional' knowledge reveals that the CD4/T-4-cell count cannot be used as a prognostic or diagnostic *until* all levels of all the subsets of T cells are known in all of the organs of the body. As the latter is an impossibility and unknowable with any degree of certainty to be of use clinically, so T-4 cell counting can never be utilized as a 'diagnostic window', that is, it should never be used in clinical practice as a measure/test. The evidence quoted supporting the statement about CD4 rate of change in AIDS challenges the central tenet of the AIDS orthodoxy in support of existing work refuting that 'HIV-mediated T-cell death' actually occurs (Papadopoulos-Eleopoulos *et al.* 1995). Also, it is indicated that clinical/observable change is clearly the most important predisposing factor to onset of AIDS, not the levels of T-cells. Thus, 'first-hand' experience constitutes particular knowledge of the count and through its resonance with other knowledges thus implicitly questions the incorporation of the T-4-cell count into a normative framework of linear progression leading through OI's to death.

'..what is going on ?..'

Anxieties are raised when the individual contextualizes personal experience in relation to such a normative frame of reference:

"I remember at one particular point about 2-3 yrs into my diagnosis that I was always told that whatever level I had was always normal that it quite clearly isn't and it might mean it would be perfectly adequate to fight off any opportunistic or serious infections but I've learned since that it wasn't normal 'cos my first test was 400 and something count which is only the bottom...it's not that I wanted to be depressed at the time ...but it's about grasping exactly

what is going and I think I have had to educate myself about it..it's not always easy..I can understand what most information is about and I know how to get it it's still difficult to work out exactly what is going on."

MARK

Thus, the "level" or the counts' absolute value is abstracted from the technic and may be considered as something separate from the body to be learnt about in terms of its 'normality'. This abstracted frame of reference is seen as useful for personal education, the adequacy of protection against infection and for judging whether one's measure of immunity is 'normal' or not, the lower the count the greater the risk/anticipation of OIs (refs). The technic's 'normal' range varies in ELISA positive patients with "minimum CD4+ cell count of 118 cell/mm³ and a maximum ..of 713 cell/mm³" where one count varies by a maximum of nearly 600 cell/mm³ (Malone *et al.* 1990 p.). Also, the USA Multi-AIDS Center Cohort study (MACS) of 4954 gay and bisexual men (Hoover *et al.* 1992) found a CD4 cell count of 300 x 10⁶/L was actually a value between 178 and 505 x 10⁶/L. There was no certainty the actual CD4 count was less than 500 x 10⁶/L or greater than 200 x 10⁶/L as measured in laboratories 'standardized' by an "ongoing quality control program" (Hoover *et al.* 1992 p.). Other researchers found decreasing T-4 cells and inverted T4/T8 ratios associated with transfusion, but no increase in OIs like PCP or KS and concluded:".. studies which define transfusion related AIDS on the basis of analyses with monoclonal antibodies must be viewed with caution" (Grady *et al.* 1985)^{xxxvi}. Further research confirms alteration of the T cell count in patients with mycobacterial infections, very prevalent in AIDS patients^{xxxvii}.

'..I didn't know then what I know now..'

In the 'at-risk' protodisease state measured by the CD4 count there is the apparent option of choosing (or not) to know the count. Yet, a lot of importance is placed upon the count as a measure of immune-deficiency and as a surrogate marker for degree of HIV-mediated T-cell destruction, the question of the option of choice may become one of conformity by coercion in practice, even from the discourse of self-help 'activists':

"SO SHOULD I IGNORE MY CD4 COUNT ?

No. CD4 testing continues to be a reliable marker for predicting the risk of opportunistic infections and for determining when it may be appropriate to start taking preventative treatment (prophylaxis) for those infections"

Poppa 1996, Body Positive Newsletter August

The primacy placed upon information-gain leads to regret when hypothetical possibilities remain uncommunicated and 'potential' decision-making is perceived as not addressed:

".. when my T cells fell last year I didn't really imagine that they could decline so dramatically so quickly it never occurred to me to ask that this was a possibility 'cos I'd experienced in all the tests you know in the last six years a very gradual decline but there was some quite massive peaks at various times so there certainly was the possibility of dramatic changes but I didn't think that I would lose say 80 per cent plus of my T cells in the space of months and it's not to criticize anybody...but in a sense it's a shame that I didn't know then what I know now I'm not quite sure what a difference it would have made maybe I would have approached things differently at an earlier stage"

MARK

The description of "..not knowing then what one knows now" acknowledges

how operationalization and utilization of this technic appears to facilitate a series of options, which may or may not be uptaken, premised on the belief in a 'normal' T cell count. If such options are not taken up, there is regret about the actual decision taken and with the knowledge of hindsight, the actual decision taken appears to have been made without the 'full' information. Also, regret about 'not knowing then what one now knows' underlines how pervasive and powerful is the internalization of 'progression', and lack of the prognostic 'fore-knowledge' ('possibility of the count falling') leads to regret. Given the strong imperative character of the technic, the reasoning appears as: it is worse not knowing that the count may go down dramatically which would indicate something bad may happen in the future and the opportunity to prevent it had been rejected by not asking if this could happen (Kenen 1996 p.1550). Thus accepting the offer to know avoids this "anticipated decision regret", an important motivational factor in the choices people make about acceptance of screening (Tymstra 1989 p.207, Bell 1982). Individuals are known to act to prevent feelings of regret through accepting the offer of screening, irrespective of side-effects or psychological and emotional drawbacks. Thus, spontaneous need for screening is non-existent, it is constructed through the personal nature of the invitation to know (Tymstra 1989). In addition, knowing or not knowing the absolute value of the count encourages a binary way of thinking about the risk of the count dropping ('happen' or not 'happen'). The trend forms a graduated or prognostic scale which has uncertain units given the time to any 'major' OI is

unknown. This is in contrast to other more nuanced approaches to the many biological and environmental factors affecting the value of the T cell count and the tests inherent (un-)reliability and (in-)validity (Papadpulos-Eleopulos *et al.* 1995)

'..my only protection is not to know..'

The orthodox understanding of progression also conveys a coded belief about a much shortened life:

MARK:"..an example when my T cells fell last year I didn't really imagine that they could decline so dramatically so quickly it never occurred to me to ask that this was be a possibility 'cos I'd experienced in all the tests you know in the last six years a very gradual decline but there was some quite massive peaks at various times so there certainly was the possibility of dramatic changes but I didn't think that I would lose say 80 per cent plus of my T cells in the space of months and its not to criticize anybody but in a sense its a shame that I didn't know then what I know now I'm not quite sure what a difference it would have made maybe I would have approached things differently at an earlier stage

Interviewer:How would you have done things differently ?

MARK:I dont know. I think that when I gave up work there was partly a sort of readjustment to a different kind of lifestyle maybe. I drifted for 18 months or so and there were things that I could have done then..things like travel and things of that kind that I'm aware that I have a decreasing amount of time to enjoy that sort of thing and I realise that I'm a just as much responsible for that as anybody else it's just..I think also that and this is the bit that annoys me to some extent with the focusing so much on being positive which I'm perfectly happy to do there is a sense that somehow the realities of the situation can get lost and the sort of campaigning thing that AIDS does not mean death well frankly it does and it's an insult to pretend that it doesn't ..you know HIV can lead into AIDS or not probably ..yes it

does over a very long period and so life isn't over when you get a diagnosis and I can accept that the sort of polemical thing to sort of encourage people not to consider their lives are over...but there is a reality which is unavoidable and I feel that I have had to ask the difficult questions because nobody has been prepared to offer the difficult truths about the realities..I live in a community where I've lost so many friends the reality is there staring me in the face but not necessarily related to me personally and I wonder how people coming into with a different experience of HIV that doesn't come such a close circle of friends how they would feel about it 'cos they don't have the personal experience they could go two ways couldn't they could be either excessively depressed about it or excessively violent about their experience of living.."

Thus, the knowledge of the trend in the count is a form of embodied or encoded knowledge. This technic in itself is endowed with power which can contextualizes and thus has potential to shape individuals' decision-making processes, in anticipation of death (awareness of having "a decreasing amount of time to enjoy" living). Yet, individuals may refuse the invitation to know:

"..for quite a period (I was asked).. "Do tell me if you need them"..but I'm not really interested in knowing because I was aware I was at a stage where hearing them used to affect me too much..

I used to really set too much store by it and I couldn't find a way of preventing myself from doing that so the minute I felt I don't need this..so I stopped..I stopped..my only protection is to not to know ..OK that probably means pushing it away from me hiding the facts from myself..although I didn't want to see it but I felt I could get through the day better without that information because in the end what

are they going to do.. what would..if I could find nothing beneficial worth knowing I felt there was no point knowing if I couldn't locate any benefit in knowing my CD4 count..it would have been easier to go through life not having that hang around me as well as HIV hang around my neck but at the same time there's a part of me realizes you've got to somehow learn to accommodate this knowledge..I don't know how I have ..but now I can deal with it ..I think it was simply actually to saying I have to deal with it therefore I'll deal with it..I know them, I ask for them, I get them.."

ALAN

In the above the test is avoided because the expected regret induced by knowing exceeded the expected regret foregone by not knowing. Thus a decision is made regarding the value of prognostic information, defined as "fore-ward knowing"^{xxxviii} said "to allow patients to view themselves differently" (Asch *et al.* 1990). However, such looks more like a *perception/construction* of utility, given this foreknowledge of the dropping T cell count seems unable to add behavioural strategies to the individual's repertoire of actions other than those relating to 'choice' about medicating using a "tool" which "can't definitely predict anything":

"It is useful to have your CD4 count measured for two reasons:

- *To monitor your immune system and help you decide whether and when to take anti-HIV drugs and treatments to prevent infections
- *To help monitor the effectiveness of any anti-HIV drugs you are taking

Monitoring the changes in your CD4 count while you are taking anti-HIV drugs can help you and your doctor decide whether your treatment is working, or whether it is time to try different options

The test is best viewed as a tool for you and your doctor to use as you decide"

National Aids Manual, 'Factsheet 3 CD4 T-cell counts' (1996a)

"So what use are CD4 counts ?

Although they definitely can't predict anything for any individual, they are useful in warning you and your doctor about the danger of getting opportunistic illnesses

So measuring your CD4 count is a way of knowing what to look out for and what to protect yourself against at the right time"

National AIDS Manual Living With HIV and AIDS (1996b)

'..something wrong in the laboratory..'

Choosing the option to know in response to the imperative nature of the technology and the media, may be additionally anxiety-laden due to the un-reported (under-reported) problematic of the technic itself:

"..actually for quite a while I've said it I've said it to (Doctor) I don't want to know we've (Doctor) and I've had long discussions about the merits of it because I was going there I had experiences of friends going through hell..because CD4 counts have gone down.

I had one ..friend..I nearly panicked here because he was so distraught ..he he had gone to the Clinic and they told him his CD4 had gone down to 10 God knows it had been at 300..now he believed it..Michael's knowledge of the whole thing was panic..

It turned out that it was incorrect or something had gone wrong in the lab-wise and..what annoys me is that they didn't even apologize to him..I said to him that can't be right go back and demand another test.. which he did and they found out it was still 300..I mean.. for me I used to not

bother with it.."

DAVID

In face of the central tenet of the AIDS orthodoxy which speaks of the T cell count as a predictor of disease progression in AIDS patients and as a surrogate marker for the degree of HIV-mediated T-cell death, being given information of one's declining count has become a traumatic experience. Yet, personal experience can intuitively question the basis of the count:

"..'cos I've heard that its diurnal ..I'd heard if you take it in the morning then take it in the evening of the same day and stuff like this..but the other reason for the morning thing too is (Doctor) said..and I knew and I knew what he was going to say and I was waving pretty fists is of course like if you can get them off in the morning you can get them back the next day because of the lab..I said OK I check that..I can buy that.. but I still feel..I still believe that it is these variations that are recorded I said because we all have biological clocks you know that rhythm changes if your biological rhythm changes according to the hour of the day and stuff like that..I am sure everything else in your body is being affected at the same time..so you know I didn't want to get bolshy with him 'cos I do like him..but I mean I couldn't..I said to him I don't buy everything you say..that's fair enough"

DAVID

Thus this resonates with less-frequently quoted research refuting the basis of this central tenet in the AIDS orthodoxy and describing what is methodologically problematic in the science of the T cell count. For example, Sande & Volberding (1990) in a medical AIDS text published 3 years before the Concorde study report, stated:"..(the) lack of universal availability, diurnal variability, and

interlaboratory variability..make it an imperfect monitoring test.." (Sande & Volberding 1990 p95-96)^{xxxix}. Grimes & Grimes (1994) encouraged nurses to practice ethically by informing patients that CD4+ counts fluctuate:".. as much as 20% within..and..between laboratories, due to multiple patient and laboratory factors." (Grimes & Grimes 1994 p.43). Papadopoulos-Eleopoulos *et al* .(1995) concluded:"..it would appear..that a decrease in T4 helper cells, the T cell count, is not sufficient for the AIDS indicator diseases to appear" (Papadopoulos-Eleopoulos *et al*. 1992). Thus, the reliability and validity of the flow cytometry for T cell counting, prior to AIDS a research tool in immunology, is so variable as to suggest its value for clinical utilization and application needs to be urgently reappraised.

"..it's interesting that the massive fall in my T cells has happened over a period when I've been taking drugs.."

However, the perceived 'objective' nature of the trend in the count, a frame for clinical decision-making about prophylaxis and anti-retroviral therapies, contrasts with the perceived 'subjective' and contradictory nature of medical (or 'clinical') judgement:

"I think part of the difficulty..the single gross difficulty that I've had is in that I like to take an intelligent an active approach to the kind of medication that I'm on is getting objective information..that I find difficult, maybe there isn't..it's subjective information because what you're prescribed or take is a matter of medical judgement and there isn't necessarily a right or wrong answer to these things because they honestly don't really know but it's interesting that the massive fall in my T cells has happened over a period when I've been taking drugs specifically Acyclovir and it's not to say that it wouldn't have happened anyway but you do wonder to some extent..and the last thing

that I want to happen really is to take a course of medication to prevent me getting something that I haven't got that ruins the quality of my life and that was my experience of Septrin and Dapsone (anti- *Pneumocystis pneumonia* drugs) and of course there are all the other things which I've not started yet like AZT and 3TC (anti-retroviral drugs) and all those and where the information I get is very contradictory."

GEORGE

Through the association of a fall in the T cell count with particular decision-making, the T cell count becomes the frame of reference through which life events are perceived, such as taking medications. In this way it resembles the process described for the genetic construction of testing in women's health, the "geneticization" of the self (Lipmann 1994 p.9). Similarly, for those judged positive on the ELISA screen, the T cell count potentially creates a lifestyle in AIDS by its framework for progression, potentially shaping issues in new ways (anticipated decision regret), translating the everyday in life (association of symptoms and events), and transforming the definition of natural ('normal') (Lipman 1994 p. 21).

That this technic is perceived of as 'accurate' or 'valid' contrasts with knowledge that it is affected by sunlight (sunbathing) and solarium exposure as much as two weeks after initial exposure (Hersey et al, 1993) and furthermore varies "between labs or because of a person's age, the time of day a measurement is taken, and even whether the person smokes" (Cohen, 1992 p.). The 'objectivity' of the count for those judged 'unwell' ('AIDS/HIV asymptomatic/symptomatic') is further

questionable given that five per cent of healthy persons seeking life insurance had 'abnormal' T cell counts and researchers finally considered that:"..low T cell numbers or ratios appear to be stable findings" for some individuals and: "..in the absence of a history of a specific infection or illness or major abnormalities in major on physical examination, it is not worthwhile to attempt to find a specific cause for the abnormality of T-cell subsets.." (Rett et al. 1988)^{x1}. This exemplifies Dutton's tort of the mechanistic thinking permeating medicine. Thus, despite the problematic in the technology of the T cell count, it is still perceived as "an aggregate of a bunch of mechanical..chemical things" that are "ultimately very definable" (Jarvik 1982 quoted in Marie-Claude Wren 1982 p.34 cited in Dutton 1988 p.20).

"..take a course of medication to prevent me getting something that I haven't got.."

Anticipated decision regret also extends to decisions based upon the count concerning whether to accept medication or not. For example, if on the basis of the perceived probability of developing an OI one accepts prophylaxis ("for something one hasnt got") regret over the previous decision-taken occurs when the prophylaxis ruins your quality of life:

"And just what do you do ? You know I can cope with the idea of a shorter life than I would wish..it's that I want whatever the length of time is to be in as good health as possible and to enjoy doing things and clearly a number of treatments do make people feel dreadful and I honestly

don't see any point 'cos the whole focus as I see it about dealing with HIV and AIDS is that it should be about quality of life and quality of life is not measured in an objective way its measured in a whole range of other things in your life some of which we have power over some of which we don't..

I suppose quality of life is to do with primarily the quality of one's relationships and primarily the partnership ones are friendships em how you spend your time having the capacity to enjoy life and perhaps accept the unexpected.."

JOHN

When the count is used as a test of when to prophylax, the question is whether to do so, an act of insurance against an assumption of probable but as yet uncertain illness. This may be outweighed in future similar situations by the experience of taking prophylaxis which may itself causes sickness. Thus the T cell count encourages feelings of regret as decisions are made under uncertainty and after observing the state which occurs, the individual may feel the outcome to be inferior to the alternate option (Asch et al. 1990). Also, prophylaxis is perceived as negatively influencing quality of life as measured qualitatively by seeing its effect over the capacity to enjoy life and one's ability to accept the unexpected, which prophylaxis negatively effects. Thus, in such reference, the T cell count is utilized for placing a quantitative frame on the experience of living, reflecting the quantitative in the 'medical-thought style' where "primarily quantitative judgements" are trusted (McCullough 1981 p.259). This may further affect the splitting of the self from the count and abstracting the individuals' experiences. It also leads to the replacement of qualitative/intuitive thinking^{x1i} with the hypothetical, which involves prior and posterior probabilities (Asch et al. 1990). In context of

the T cell count this could become an impossibly complex operation, if a wider appreciation of the actual biological and environmental variables governing the validity and reliability of the count were factored-in by the individual (Papadopolus-Eleopulos *et al.* 1992). For the orthodoxy, the key test for administration of prophylaxis is the value or trend in the T cell count. T cell counts of 200mm^3 and 500mm^3 are defined points, "medical descision points" (CDC 1997 p.22), within the orthodox framework of the count at which individuals are advised to begin prophylaxis for *Pneumocystis carinii* pneumonia (PCP) and treatment with antiretroviral therapy, respectively.

"..we have the doctor with his opinion and me with my own view of what CD4 counts mean.."

The frame of understanding about this technic may differ radically between patient and physician:

"..on the simplest level I would think its like we have the doctor with his opinion and me with my own view of what CD4 counts mean then you can get a conflict of (interest) he (the doctor) is trying to give me these results he's making absolutely no judgement regarding these CD4 counts I'm coming from a world where people look at CD4 counts with a hell of a lot of judgement ..he's handing them out to me without any judgement whatsoever there's something in conflict because I'm saying "Well..what are you saying ? Are you saying anything ? Are you just giving me a figure here ? .. Tell me what do you think these figures mean ? " ..I can then tell you whether I think it's valid for me in you know ..does it accord with how I feel and if it doesn't dramatically what's wrong with the figures because I can't deny I'm living in my own body my own self my own body is telling me this..I am not you.. all my life I've had to listen to me 'cos that's the only thing I know to be true..I can't say that you really exist.. I'm not inside you..d'you understand what I mean..'cos that's extreme can you see

what I'm trying to get at ..this is all I have to go on in my life ..me what I feel what I've experienced what I think what I hear coming from inside..so..whatever he's saying to me I've got to equate with what I feel now..ideally he should question me about my feelings about CD4 counts how I feel when I hear them how am I going to react in order to get into the world my world of CD4 counts my world of reaction to CD4 counts and stuff like that again it's difficult what have we got..we've got an hour at the most usually half an hour appointments you know some (Doctor) has more than two three-quarters 'cos he was very much more relaxed type of..you got this time for him..I can't expect too much of him so I don't know the answer I don't know what he..whether there's another method of relaying them.."

ALAN

Thus, the individual may come to frame the count in terms of how well it accords with personal experience/knowledge and feeling. Within this frame of understanding, if the T-cell count does not accord with the individual's personal experience/knowledge and feeling then it begs the question "what is wrong with the figures" rather than what is wrong inside the body. This frame of understanding is a form of enablement/empowerment in the sense that the orthodox meaning of the count (signifier) changes as the meaning of the signified (target information) shifts or is displaced away from the body and onto the technic. Thus, the signified (target information) becomes the validity and reliability of the technic, rather than the individuals 'immunocompetence' 'risk of OI', 'need for prophylaxis' etc. In this way, the orthodox meaning of the count is displaced/shifted or resisted and replaced with another. This shift may be based upon personal understanding/experience (knowledge) and feelings as they strike a dissonance with the orthodox meaning of the information being given,

as the individual understands the information within another frame of reference without its overly negative connotations or 'orthodox nuances'. Hence, other methods of interpreting the meaning of the count are suggestive of different frames of reference and understanding. In addition it is described how individuals may develop such understanding through experience:

Interviewer: "How was it that you didn't 'buy' the information about the count going down ?.."

ALAN: "...It wasn't one of the experiences that I'd had with people..other people I've thought to myself I don't see why it should be that much different you know

...basically I think it's a result of spending a lot of your life..about 15 years around doctors around clinics, hospitals, whatever..visiting friends who are unwell in hospital and dying people seeing lots of different nurses lots of different attitudes with handling the same similar situations..some might say it makes you get more skeptical it's something like that.. you get a bit.. you get these injections of reality..and you realize (why) you see other things is..for good or bad one thing that (we) managed to gain (as well as) is (the feeling) this new thing where doctors level with us..bit more.. well one of the off-shoots of that is that you suddenly realize is that hey these people are not god they're not god they're not invincible they are as prone to mistakes as any other human being you know and so (he's were) just as (in)capable so let's try and listen carefully here.. you know..in terms of how we take on the information that's given to us..as much as we trust in it..basically in where nothing they say to us must no longer be gospel..

You know before HIV...anything a doctor said to me would have been gospel I would have taken it fine no quarrel with that but now I think yeah OK I've heard that..now let me see let me think now what do I think of that..what do I think..is it what

I want...is he levelling with me.."

DISCUSSION OF FINDINGS

The orthodoxy claims immunosuppression in AIDS is assessed by measuring the numbers of T cells in a sample of blood removed from the body. This measurement is utilized to construct a framework within progression through the protodisease state to AIDS is situated. Thus, within the orthodoxy, the count provides an abstract and normative frame of reference which individuals may internalise and with which they can potentially shape their lifestyle. It provides a quantitative measure of apparent 'objectivity' with which to compare symptoms and contrast general life events. The latter and the public expectations of technology enable a 'purchase' ("one objective measure") to be had on the vagaries of the illness experience. Public expectations of technology are founded on the 'exactness' of laboratory diagnosis, earlier described by Halpenny as the "real lure" which "everyone knows is scientific" (Halpenny 1924 p.672) and which historically raised the profile of the laboratory in medical practice (Reiser 1978).

From discourse on the T cell count, the T cell count facilitates the shaping of a lifestyle in AIDS, through abstracting the count from the individual's experiences and further splitting the count from the 'self'. Through the creation of a trend, the count constructs a normative framework with which to judge normality from abnormality, with a perception of foreknowledge about the falling count in

anticipation of illness. In so doing, it appears to offer a virtual array of hypothetical options, or an algorithm, which leads to anticipated decision regret when posterior decisions (those already taken) appear with hindsight to be wrongly-based and appear not to be the 'right' choice. Within such a frame of reference, the taking of prophylaxis is an application of hypothetical thinking with which to defeat the unexpected and 'objectively' increase quality of life. In this way prophylaxis can be experienced as an insurance against an orthodox probability of developing OIs. Also, the T cell count's numerical and 'objective' laboratory-nature elides the actual problematic (its scientific validity and reliability) whilst enhancing the *perception* of scientific validity and reliability.

Furthermore, the experience of the T cell count invokes differing frames of reference and types of knowledge which may be described as personal, professional and social. For example, following a positive ELISA screen and embarking on a "patient-career", an individual's personal exposure to the "same similar" situations, such as the recursive experience of T-4-cell counting in the clinic, can facilitate the development of experiential knowledge which leads to a re-configuration of the meaning of the count. This meaning contests the authority of the 'count' and displaces the orthodox meaning of the count (signifier) away from the body and onto the reliability and validity of the technic itself. In this example of empowerment, the orthodox meaning of the count is powerfully displaced/shifted or resisted and replaced with

another. Thus, a dissonance with the orthodox model is created. In addition, this latter knowledge plus the information provided by professionals who "level with us" further facilitates an awareness of professional fallibility. Thus, trusted information may come to be perceived-of/realised-as problematic, not so much in how it is transmitted ("method of relaying") but in how information about the declining T-4-cell count (meaning 'HIV-mediated T-cell death'/the accepted prognostic meaning or understanding) is "taken up" by the individual.

In context of the above, a critique of empowerment may provide a basis for understanding how individual discourse on the T cell count has the potential to position the individual in relation to the existant discursive fields. The latter are exemplified by the speaking positions assumed and the stances formed within the discourse, as representative of the orthodoxy ('assimilation') or as representative of a reverse or counter discourse ('resistance'), like Tony's or Alan's. Such latter re-positioning of meaning may be heard in the discourse on T-cell counts of those (mis-) labeled as 'AIDS dissidents' and thus may be described as characteristic of empowering reverse discourse. For example, self-help and activist groups which challenge the basis of AIDS science:

"PRESERVAR LA INTEGRIDAD GENETICA, DEMONTAR EL 'SIDA', VENCER EL
CANCER

Barcelona Spain 6 to 15 March 1998

1.the official hypothesis 'HIV'='AIDS'(=death) is completely erroneous 2. the official treatment are poisonous, tending to lead to death, and their use should be halted immediately; 3. **The so-called "T4 lymphocytes" do not perform the function which was attributed to them and their level in the blood is not significant, measuring the 'T4' cell count should be stopped since it is psychologically destructive** 4. PCR is being used in a way which is completely wrong. To measure what they call the 'viral load' to apply the label 'seropositive' and to justify the introduction of the extremely dangerous 'protease inhibitors'. The reliable should be banned in 'AIDS' and if possible 5. the misnamed 'AIDS tests', which are not in the least reliable should be banned.

Centro Oncologico y Biologico de Investigacion Aplicada
Asociacion C.O.B.R.A"
(emphasis added)

Also:

"Why CONTINUUM ? The orthodox view on AIDS holds that it is caused by a virus known as HIV that is transmitted through the exchange of bodily fluids. Once infected, a person will remain well for a time, though infectious to others, before going on to develop AIDS and dying. Despite the huge sums of money spent on medical research, there is still no cure, just drug therapies said to slow the progress of the disease, and regular T-cell counts to measure health. A whole industry has evolved around AIDS, on which many careers and businesses depend, but which offers little hope to those affected. It works on the premise that HIV=AIDS=DEATH.

CONTINUUM began as a newsletter encouraging those affected to empower themselves to make care and treatment choices. As we look further, anomalies in the orthodox view continue to appear.

Are you aware, for example, that the link between HIV and AIDS has never been more than hypothetical ? That a growing body of scientists and doctors throughout the world doubt that HIV causes AIDS ?

At the onset of the "epidemic", the hysteria that resulted from the linking of sex, death and infectious virus created a climate where to question the "facts" was considered reprehensible. Many of those who dared to do so were silenced or ridiculed. Since the growth of the orthodoxy, those who question have also had to contend with the weight of vested interests.

Twelve years after HIV was first associated with AIDS many predictions based on the viral hypothesis are failing to materialize. **CONTINUUM** is a unique forum for those in the scientific community challenging the orthodoxy and those whose lives have in some way been touched by the hypothesis.

CONTINUUM is a voluntary organisation dedicated to providing information we believe is necessary for the fuller understanding of HIV, AIDS and immunity. All our workers are unpaid and the organisation relies on subscriptions and donations to maintain its work. Your support in any way is greatly appreciated." (Continuum, 1998 p.1, emphases in original).

Thus, such discourse makes redundant the orthodox meaning of the absolute value and trend in the T cell count. Thus, individuals' discourses on the meaning and experience of the T cell count, (parallel illustrations of the self-help/'empowerment' process as individuals strive to understand/develop personal meaning), maybe discourses of assimilation or cooption when the discourse positions individuals' understanding/meaning within the orthodox model of AIDS. Therefore, empowerment in AIDS may be seen as a dual process either as one of resistance against, or as a process of cooptation (Zola 1987 p.33) or assimilation within the 'orthodoxy' or dominant "AIDS thought-style", the 'medical model' of AIDS (Horton & Aggleton 1988).

However, such a presentation/discussion of the data ('assimilation' and 'resistance') may be too literal an interpretation of what appears, or is perceived of, as a 'binary opposition' ('orthodoxy' v. 'resistance') where actually a spectrum of opposing and counter posing speaking positions may exist within individuals' discourse similar to Foucault's conception of discourse as: "a multiplicity of discursive elements which come into play in various strategies" and not: "a series of discontinuous segments...**not**...divided between accepted and excluded discourse...or...the **dominant and dominated one**" (Foucault 1976 trans. 1978 p.100 emphases added) as discourse is seen by Foucault as: "both an instrument and an effect of power" that is: "a point of resistance and a starting point for an opposing strategy" (Foucault 1976 trans. 1979 p.101). The danger here is one of collapsing the data into void where such a pre-conceived polarity may not lie or even exist. Following on from the previous discussion of Tony, and in context of nursing experience in AIDS (Corbett 1997a 1997b), such supposed binary polarities ('orthodoxy'/dissidence') can appear more like rhetorical/political constructions. The latter are most certainly useful for understanding the immunological, virological, and biophysical problematic in AIDS science, and may be politically useful for 'AIDS activists' when such an orthodoxy is threatened (Watney 1997 p.85), but has doubtful utility for understanding the material and expedient imperatives often felt or lived through by individuals^{xlii}.

THE PROBLEMATIC IN CD4+ T-CELL LYMPHOCYTE COUNTING

Empowerment

AIDS discourse on the T-cell count may be described as empowering when enabling individuals to deconstruct/reconstruct their understanding of syndrome. This development of personal knowledge and understanding of a particular material condition is central to self-help/empowerment (Wann 1995 p.ii). Yet for AIDS, empowerment is a double-edged process and can be an assimilation process if functioning to coopt understanding within the biomedical model of AIDS. The political utility of such processes, and it is argued its significance for this examination, lie not just in empowerment's 'reformist' roots^{xliii} but in its 'reality' of enablement; the individual becomes 'empowered' through gaining information and knowledge and is re-positioned from helpee to the agency of self-help. But utilizing "who's knowledge", "who's information ?" (ref).

Secondly, an individual may appear to be gaining more knowledge, or becoming 'empowered', whilst at the same time their understanding of AIDS is actually being constrained by or assimilated within dominant or 'mainstream' (biomedical) modes of thought. Thus, within this context, 'empowerment' may either act to reposition individuals' own meanings and understandings within this orthodox discourse of allopathic^{xliv} medicine by coopting the mediating effects/structures of self-help for purposes of relating groups and individuals to the

ideology of biotechnology. Or, empowerment may also enable contestation of the understandings embodied in dominant biomedical constructions of AIDS through utilization of the multiple discursive "frames" through which one may understand AIDS.

Cultural imperatives

The T cell count embodies several characteristics of tests as extensions of modern day screening of the body. Its methodology is problematic to a degree which questions its continued clinical utility within ethical practice. In as much as the T cell count represents something which may be in part constrained by 'nature', but which has undoubtedly been brought into the human domain, shown by the data, then following on from Harrington (Harrington 1996) what are the specific 'cultural imperatives' embodied within the utilization and application of this technic that allows it to potentially shape an illness lifestyle, given that the forgoing data shows varied frames of reference whereby patients internalize its normative and quantitative framework to a greater or lesser extent ? Also, what does such then tell us concerning the science which underpins this technic ?

There appears to be several imperatives underpinning utilization and deployment of this technic. Firstly, its privileging of laboratory science is telling. Since the nineteenth century the laboratory has enjoyed a growing fascination in medicine; its prominence fuelled by individuals' expectations of technology's benevolent

appeal/potential (Reiser 1978). As Dutton states: "So deeply embedded is the role of technology in our culture that the term "innovation" is often used as it were synonymous with *technological* innovation" (Dutton 1988 p.25). For example, AIDS 'activists' (Horton 1989) viewed the T cell count as a useful surrogate marker even though it had never been subjected to rigorous methodological evaluation and its gross limitations for the orthodoxy were known long before the Concorde study reported. Thus, the expectations raised in AIDS for this technic were based upon other (perhaps cultural) imperatives besides that provided by public fascination with the latest technology.

Secondly the count's perceived utility as a 'biological marker of disease progression' (Levacher et al 1992) is also interesting and represents part of the transformation of the aims of medicine through the application of biology, which Pellegrino describes as producing an overarching focus on "things to do for a particular disease that are *measurably* effective" (Pellegrino 1985 p.10 emphasis added). Following Pellegrino, the T cell count *appears* to do something for a particular disease and which is *measurably* effective only resulting in a measurement. Therefore, the significance of the T cell count lies in its seemingly 'objective' and 'scientific' (laboratory medical) nature which appears to measure or 'stage' disease/illness.

It is precisely this *perception* of quantitation and staging of the 'natural history' of the disease by which the T cell count assumes

a totemic quality in AIDS. It embodies key notions in the AIDS orthodoxy of progression, disease-staging and the technic for 'marking' ('totemic') those affected. Also, its metaphoric and metonymic signification for AIDS and retroviral causation also stems from this totemic quality of being able to 'mark'^{xlv} those 'at-risk' (Kenen 1996). For example, pre-identification of HIV, at the time when the AIDS orthodoxy was struggling to make sense (construct) of AIDS, the state of immunocompetence in AIDS was 'defined' by utilizing this reading of the body as one "speculative mechanism" (Rosenberg 1992 p. xvii) for understanding the clinical immunodeficiency of AIDS. Thus, historically this technic became the first "explanatory and classificatory" (Rosenberg 199 pxxiv.) scheme for AIDS. It emerged from research immunology at a time prior to the invention of ELISA screening when the principal diagnostics were clinical examination and bacteriological/virological laboratory culturation. Thus, T cell count was perceived as enhancing AIDS diagnostics in support of the then "current view of AIDS as an immunodeficiency disease" (Pinching 1986 p.36). Its link to retroviral causation may be seen in practice. Here it is often performed on individuals perceived of as being 'at-risk' through their own disclosure of so-called 'at-risk' 'sexual behaviour' meaning perceived of as being 'at-risk' following others' negative perceptions of sexuality difference, like that of gayness (James *et al.* 1995) and/or ethnicity. In such 'professional' health care contexts, the latter individuals can potentially become subject to T cell counting as a surrogate for ELISA screening, if their 'consent' for ELISA is

not forthcoming (James *et al.* 1995).

Thirdly the clinical utilization and application of the T cell count may have had cultural imperatives for AIDS medicine. In addition, and prior to 1984, the growth in medical technology was characterized as a degeneration from professional autonomy to a radical monopoly creating a social iatrogenesis which "...abolished even the right to self-care" (Illich 1975 p. 49). In the late 1970s/early 80s medical technology was popularized as a "major threat to health" and the United States CDC organised "disease hunts" (Duesberg 1996) and marketed the concept of the (empirically unproven) "periodic health examination(s)" (Siegel 1966 p. 292-295). In that context, and given the emergence of AIDS which at the time appeared to pose a challenge to science (MMWR 1982) and clinical practice (Bennet 1986), the ensuing pressure for a technological fix to the emerging 'epidemic' was great.

Fourthly given the clinical imperative to define AIDS and to do so through accepted traditional means, whereby it would be comprehensible like other 'fatal' diseases such as cancer, the newly emerging technology of T cell counting provided an opportunity to stage the phenomenon of AIDS. This was achieved by becoming a test of immunocompetence and progression in AIDS. The CDC criteria (CDC 1992, 1986) and the Walter Reed Staging Classification (Redfield *et al.* 1986) are based on the understanding of T cell counts as normative representations of immunocompetence. These schemas made AIDS clinically comprehensible

to a generation of health practitioners based upon a tradition of disease staging or 'natural history'. In addition, staging systems addressed and satisfied the cultural imperatives of AIDS activism which perhaps rightly, but somewhat hastily, sought applied technology for prediction and treatment of disease/illness.

Lastly, following on from the above imperatives, the trend for T cell counting fuelled differing ideologies; on the one hand, AIDS activism with its "drugs into bodies" sloganeering, to some extent facilitating radical change in the US FDA regulations, recently characterised as a "rush to judgement" (Shenton 1998 p.245), whereby 'fast-tracking' of experimental medications onto the market now occurs through the expanded access mechanism (Epstein 1996). Whilst on the other hand, the medical ideology of screening/testing utilized T cell counting in diagnostic/prognostic screening. The latter increased the observed prevalence of AIDS by lowering its detection thresholds (Papadopoulos-Eleopoulos *et al.* 1995, Black & Welch 1993, CDC 1992) and thus, more importantly, lowering the 'treatment thresholds' as prophylaxis, therapy for OIs and antiretroviral therapy are all predicated to a greater or lesser degree on this count.

'Dissidence' and 'orthodoxy'

For the moment leaving aside the key issue about what current understanding of the CD4+ count implies for the 'HIV-AIDS hypothesis' (not 'HIV-mediated T-cell', so what is it ? "A bit like apples not

falling to the ground if you adhere to the theory of universal gravitation"^{xlvi}), there is the other issue concerning the technic's utility and application in clinical practice. In context of the epistemology of social constructivism, social science research in AIDS appears to either invalidate (Barosso 1997, Wong-Wyllie & Jevine 1997, Epstein 1996) or ignore (Waldby 1996, Siegel & Kraus 1991, Weitz 1989) individual experiences which question some of the basic assumptions lying at the heart of the AIDS orthodoxy, such as retroviral causation and how HIV kills T cells. This is often based on the notion that 'scientific truth' is socially constructed (which it maybe) and thus the essentials in AIDS science, which clinically/ethically impinge on the material well-being of patient/clinician alike, as 'social constructions' can be conveniently 'bracketed' (meaning side-stepped or disregarded). Thus, it is arguable that social science may have elided the difficult "clinical reality of HIV and AIDS" (Treichler 1992b p.97)^{xlvii} and the material affects of "disease definition" (Rosenberg 1992 p. xxiv) on individuals by 'black-boxing' the problematic in AIDS science. Yet, social constructivists describe AIDS science as "dialectical/undetermined/underdetermined" (Fujimura & Chou 1994 p.1032). Given what Lipman describes as the "geneticization" of life or the biomedical redefinition of "human geography" (Lippman 1994 p.9), which AIDS science is very representative of, social science cannot afford to elide the problematic in individuals' clinical experience in AIDS; otherwise Lupton's tort of dismissing or obscuring the very real debates on the constitution of truth in AIDS is truly

warranted (Lupton 1995a p.84)^{xlviii}.

This is not to deny the reality of illness or disease, quite the opposite, it is to understand the basis of it and for development of effective strategies for prevention and care. Following Lipman, such controversies are not binary/polarized oppositions between "experts promoting technology and Luddites trying to retard science" (Lipman 1994 p. 29) or between the 'AIDS orthodoxy' and 'AIDS dissidents' (a debacle both binary and polarized). These distinctions are employed often for semantic/analytic and descriptive purposes, (as in this paper). Yet, "who's knowledge ?" and "who's information ?" are important questions to clarify in AIDS as much of the so-called 'basic' science is controversial, heavily nuanced and open to interpretation. Yet, in trying to transcend the binary opposition what may be referred to as the AIDS 'orthodoxy' and 'dissidence' appear to resemble the types of knowledge which Stephen Cole has described as existing at the 'core' and the 'frontier' in science (Cole 1997, 1994, 1992). The 'core' is "...a small group of theories, methods and exemplars that are almost universally accepted by the relevant scientific community as being both true and important". The 'frontier' is "all newly produced knowledge...most ignored...small part paid attention to, and most of that is discarded as being wrong (Cole 1994 p.133). Thus, this model can accommodate the continuing controversy over the 'HIV-AIDS hypothesis'. At the 'core' of AIDS science there is the accepted theory of retroviral causation, whilst at the frontier lies

AIDS dissidence, where its position to borrow from Treichler may be likened to that which:"..contests the terrain of AIDS discourse on technical analytic terms." This highly engaged position is:"..quite different from New Age articulations of "the natural".." (Treichler 1991 p.100-101) as it utilizes AIDS science to deconstruct the orthodoxy of the ELISA screen (Papadopoulos-Eleopoulos *et al.* 1997, 1996), the Western Blot (Papadopoulos-Eleopoulos *et al.* 1993), the meaning of the T cell count (Papadopoulos-Eleopoulos *et al.* 1993) and also the 'isolation'/identification of HIV (Papadopoulos-Eleopoulos *et al.* 1998, 1997). Such can never to be confused with New Age articulations, nor should such be misrepresented as "conspiracy theories" (Watney 1997 p.85) as they speak from an engaged position which contests the AIDS orthodoxy from within differing 'paradigms' of scientific thinking (Kuhn 1972, Feyerabend 1975).

Surrogacy and testing

The T cell count is representative of a historical trend, the abandonment of subjective clinical evidence ('what the patient says', 'what the physician observes') and its "substitution by a devotion to technological evidence" ('what the machine says') (Reiser 1978 p.230). In this order of things, the body is perceived through a screen of diagnostic/prognostic technology applied by specialists; it works to relinquish control over the diagnostic/prognostic process itself. Most physicians are not immunologists and only have cursory understanding of the basis of the T cell counts' reliability and validity

or indeed the equipment, processes and criteria utilized in the laboratory for its production. Thus, it recalls Almroth-Wright's description of "treatment by correspondence" or "interpretation by delegation" (Almroth-Wright 1910 p.8) and latterly Atkinson's description of modern technological probing into bodily systems (Atkinson 1995 p.61) which disperses or 'anonymizes' such bodily traces for deciphering by observers removed from the individual. The delegation of knowledge and technique inherent within such as the T cell count often occurs in the context of the physician's lacks a working knowledge of the techniques of the analysis and the criteria used to make judgements concerning the outcome data. Thus, without such knowledge physicians may not adequately subject laboratory evidence to medical scrutiny and as noted by Piickering as long ago as 1955 "...to rely on data, the nature of which one does not understand, is the first step to losing intellectual honesty. The doctor is peculiarly vulnerable to a loss of this kind given, *since so much therapeutics is based on suggestion...*" (Pickering 1955 p.925 emphasis added).

Currently, important material concerns depend upon individuals' decisions and understandings about AIDS science, which Epstein aptly terms "impure science" (Epstein 1996); such include living/dying and ethical/humane medical practices. However, there are also 'futures' markets in biotechnology and pharmaceuticals to consider. For example, the emerging field of bioinformatics uses \$2 billion annually for IT research alone (Snape 1998), in order to 'identify' drug targets

through DNA sequencing from human tissues and epidemiological information. Drugs are being designed in 'factory-like' research so as to create new medicines in months rather than years, by 'automating' the testing and application of drugs through "virtual clinical trials" (Snape 1998 p. 29-33).

However, through creation of virtual trials there is the risk of virtual illness, through the erosion of the 'clinical' and the seemingly unlimited licensure given to the 'biological' in modern screening technology (Black & Welch 1990). Hence, the ethical basis of what is proposed remains less than certain. Those 'diagnosed' with falling T cell counts and judged positive on ELISA screening and having no clinical pathology are encouraged to take experimental and potentially toxic medication in the USA and to a lesser extent in the UK. Most recently, concern was voiced from within the AIDS orthodoxy about such 'innovations' reported in Shenton (1998). For example: "I am uncomfortable about the emphasis on early intervention when we really don't know what's the right thing to do...Without any drugs 50% of people will still be perfectly well ten years after they become infected. We may not have the right drugs to commit people to many years of therapy" (Weller 1997 cited in Shenton 1998 p.244, NAM 1997b). 'Early intervention' is based on 'sophisticated' screening/testing technologies and surrogate tests/markers, including T cell counting but also others of dubious validity such as 'viral load'/PCR^{xlix}. Surrogate tests "create the main difficulty in evaluating technological processes,

because these tests do not identify the disease, but rather something we **hope** will denote the disease" (Horwitz et al. 1984 emphasis added). Sox describes the interpretation of a test result in terms of the social context which 'frames' the outcome, the prior probability of disease before doing the test. In the case of AIDS, the prior probability of disease before CD4+ counting was only available through epidemiological tracking of 'risk-groups'. Thus, the post-test probability of disease was increased with CD4+ counting in at-risk individuals, thus altering the "probability that the patient is diseased" (Sox 1986) and relating diagnostic testing to treatment action when a positive test occurs (low CD4+count) in an at-risk group patient, but not when a positive result happens in a low risk patient nor a negative result in a high-risk patient (Sox 1984 p.278). As the latter is premised on 'cultural' notions of what constitutes 'high'/'low' risk, Sox shows how tests only provide statements about the probability of disease and even with careful interpretation of test results, they can still mislead as they are framed within shifting social definitions of 'risk'; only the 'test of time' can the apparent error come to light (Sox 1986). However, as the literature has revealed, and the data described, the reliability and validity of the T cell count has not weathered the test of time and has furthered invasive screening. Thus, through its totemic quality of marking 'at-risk' ('immunocompetent') individuals the T cell helped signify AIDS as a disease of certain risk groups.

In health care practice (the 'coal face' of the 'clinical' in 'clinical medicine/nursing') where clinical decisions affect people physically, psychologically and spiritually (Horwitz et al. 1984), hoping that the surrogate marker is measuring what we think it is measuring is just not good enough. This constitutes an ethical dilemma for those advocating T cell counts for prescribing medication in the absence of clinical disease. Thus, the latter exemplifies what Black & Welch (1990) describe as the ultimate ethical danger of modern medical imaging and/or screening technologies, which allows: "...many patients to be labeled with diseases they do not really have, and many have been given therapy they do not really need". Thus, where the utilization of surrogate markers such as the ELISA screen and the T-4/CD4+ count together foster the prescribing of antiretroviral therapies to patients solely on such markers, as currently common practice, and in the absence of any demonstrable clinical disease, or even symptoms, treatments are thus treatments by surrogacy and *surrogacy alone*. The 'brave new world' of antiretroviral AIDS therapy, based on the 'new' virology (King 1997 p.14-26)¹, is pushing to make "surrogate markers the sole criteria of whether or not therapies and drugs actually benefit patients" amid AIDS scientists calling for the end of clinical end points in AIDS drug trials (Rasnack 1997 p.4). Thus, such contributions to "the development of AIDS science" (Epstein 1996 p.294) achieved by pressure for incorporating T cell counts into diagnostic criteria and further into clinical practice need reviewing in light of our knowledge of hindsight concerning the invalidity of the technic for

ethically sound clinical practice. There are salutary lessons concerning the issues of methodology for evaluation of surrogate markers following the rush to incorporate the invalid T cell count into clinical practice¹¹.

Finally, whilst the cognitive content of AIDS science underpinning the T cell count appears to be common or as Cole says "constrained by nature" (Cole 1992 p.), the historical focus on the immune system for the construction and the interpretation of the meaning of this technic, and its relationship to the protodisease state engendered by such testing, is influenced by social variables and nuanced processes. For example, the origin of the T-cell-metaphoric/metonymic signifier in AIDS lay within the very early CDC conjecture about "some aspect of homosexuality" predisposing individuals to immune dysfunction and infection "on the basis of five cases from a single community" (Oppenheimer 1988 p.271). However, the cognitive content of what nature may constrain is always contested as shown by the changing meaning of this content in respect of the T cell count which has shifted and changed over time.

Given what is today known about the T cell count's methodological flaws, the historical over-inflated optimism for this technic may actually have damaged individuals through the count's institutionalization within disease defining criteria for AIDS (CDC 1992) and its ability to effect/shape a lifestyle outside or within the illness experience. This is illustrated in the

pre-determined/over-determined discourses of people so diagnosed which reveal orthodox AIDS knowledges are representative of a science which actually is "dialectical/undetermined/underdetermined and under continual (re)construction" (Fujimura and Chou, 1992 p. 1032).

However, such a science may not be that useful for developing treatment algorithms if it contains within itself the prospect of injury to the patient. Thus it is shown that at the very least the T cell count is capable of affecting individuals' thinking and shaping their lives in the anticipation of illness and its implied outcome of dying. This is what Michael Taussig calls the "clinical construction of reality" when the physician has a "powerful point of entry into the patients' psyche" with the potential to destructure "the patient's conventional understandings and social personality" (Taussig 1980 p.4). Returning to the opening narrative of this paper, Tony strove to familiarize himself with AIDS science may be in order to overcome what Taussig describes as the "powerful point of entry" into the psyche which can destructure the self. Yet, his familiarization with the science was challenging to colleagues many of who were unable to dialogue with the orthodoxy as reflexively as Tony. As a nurse working latterly in the 'AIDS field', I felt like being on the threshold of Taussig's 'point of entry'. This was an uneasy intermediate position from which one could ascertain the patient's inner psyche, but also the nature of that which constructs and so constitutes the orthodoxy, about which, long before AIDS it was stated:

"It is a good rule to make your patient respect you for

your diagnostic ability, and love you for your earnest and sympathetic attention; but nothing so destroys your psychologic influence as to encourage or allow familiarity on the part of the patient. First it is certain to add to the burden of your work and later you are sure to lose that delicate psychologic control over him, or fail to maintain yourself in his estimation on that high plane from which you may yield the greatest and widest influence over his mind." (Kimberlin 1912)

NOTES

- i . In this paper the 'AIDS test' meaning the 'HIV antibody test' will be referred to as 'judgement of positivity on ELISA screening' or words very similar. The ELISA stands for: "...enzyme-linked immunosorbent assay" and "...involves incubating a sample of blood serum with a mixture of 'HIV specific' proteins. The ELISA is positive if the solution changes color to a certain density, thereby indicating a reaction between the proteins in the test kit and the patient's antibodies. Because the ELISA is not specific, and can react to non HIV-generated antibodies, most testing authorities strive to eliminate 'false positives' by repeating the ELISA test...The Public Health Laboratory Service in Britain ..rely on only the ELISA test". Another more specific test the Western Blot is banned in the UK but utilized in other countries, an example of the large variation in diagnostic testing and hence definition of HIV/AIDS. "Test results are reached, ideally, through a process of multiple sampling which involves running several ELISA tests on one sample and then sending it for confirmation to another laboratory using a different test kit." (Shenton 1998 p.228)
- The rationale for referring in this paper to ELISA rather than 'HIV test' is to further awareness about the fact that such a 'test' is portrayed in a reductionist manner in most health care discourse, unlike the detailed description above. The effect of such reduction may act to obscure the fact that such a 'test' is really a clinical judgement, made in a laboratory by an operator who is making the judgement with information about the sample donor's 'risk' status which is used to interpret the so-called 'objective' high/low levels of donor's sera reactivity to the monoclonal antibodies, also judged as those of the human immunodeficiency virus.
- ii . Berger and Neuhaus (1976) discuss the 'megastructures' of society (eg. government, big business, powerful professions such as medicine) and the 'mediating structures' (the family, neighbourhood, church and voluntary association) which have our "universal endorsement" and as representing the sites of our "real values" (value-generating) and as the repository of our "real needs" (value-maintaining). Thus voluntary/self-help organizations are mediating structures as they relate groups and individuals to powerful ideologies and interest groups.
- iii . For example, the British National AIDS Manual (National AIDS Manual 1998) and the AIDS long-term survivors journal *Continuum*.
- iv . Horton and Aggleton argue that the AIDS research paradigm is a "post-hoc rationalization" because of the chronological isolation of HIV after the emergence of clinical AIDS. They further state that: "Following Feyerabend's (1975) critique of the history and practice of science, we should be wary of post-hoc rationalizations such as these. HIV was not isolated and identified until long after AIDS had first been diagnosed. The effects of scientific histories of this kind are many and varied, but we should recognize that in this case at least, one result has been to squeeze out from the open arena of debate, alternative accounts of AIDS" which are: "competing or complementary modes of explanations of the syndrome" (Horton and Aggleton, 1989; 76). Within this scenario of the "consensus view" they state that there are many "contestable issues" such as the: "characterization of AIDS as a sexually transmitted disease, rather than as a blood borne viral disease" (Horton and Aggleton, 1989; 76) as the Hepatitis B model prefigured AIDS and upon which the epidemiology of HIV was founded.
- v . For example, 'oxidation-reduction' as a theoretical basis for therapeutic intervention and health maintenance (Papadopoulos-Eleopoulos *et al.* 1997, 1995, 1992, Papadopoulos-Eleopoulos 1982).
- vi . A definition of the 'orthodox' position in AIDS is: "The orthodox view on AIDS holds that it is caused by a virus known as HIV that is transmitted through the exchange of bodily fluids. Once infected, a person will remain well for a time, though infectious to others, before going on to develop AIDS and dying. Despite the huge sums of money spent on medical research, there is still no cure, just drug therapies said to slow the progress of the disease, and regular T-cell counts to measure health. A whole industry has evolved around AIDS, on which many careers and businesses depend, but which offers little hope to those affected. It works on the premise that

HIV=AIDS=DEATH" (Continuum 1998 p.1).

- vii. I will use the term 'technics' throughout this paper to refer to the T cell count and its technology of production. I use this term in same way as Pickering who stated: "The second disorder arising from the growth of science and technology may be termed the fascination with machines. This disorder is one which manifests itself with unusual clarity in the field of medicine. As year succeeds year, some new physical and chemical **technic** and some new and elaborate machine are applied to the study of disease; great claims are always made for the precision of the answers yielded by these **technics** and machines. One of the greatest struggles that a practicing doctor has is to keep up-to-date with advances of this kind. No sooner has he mastered one than another is upon him. Moreover, the machines or **technics** are often so complex he cannot understand them. He has to take what they tell him on trust. It must be within the experience of many of us that there is a growing tendency for doctors to rely on the information given by such **technics** and machines in preference to the information which they gain themselves from the history and physical signs. I am extremely doubtful if this is in the interests of good doctoring." (Pickering 1955 p.924-925).
- viii. This examination may be seen as similar in aim to others analyzing of the meanings and experiences of HIV antibody testing (Lupton 1995b, 1995c).
- ix. T cells are considered to originate in the human bone marrow and mature in the thymus gland, hence the prefix "T".
- x. The human immune system is thought to protect "individual(s) from invasion by infectious organisms" (Sigal & Ron 1994 p.16) through key effector cells, "the T(-4)-helper cells which activate specific disease-fighting cells" and the "T(-8)-suppressor cells that tell the immune system when the threat ended" (Shilts 1987 p.43). "T-cells...may cause death (cytotoxicity) of antigenic cells or initiate inflammation in response to an antigenic stimulus (delayed-type hypersensitivity). Other T cells have regulatory, rather effector, role..T suppressor cells..may not be a distinct subpopulation..(Chapel & Haeney 1993 p.14).
- xi. Tedder states: "the virus needs to get into the lymphocytes and.. does so by attaching itself to a receptor on the surface of the T-4 lymphocyte" thus the "T-4 antigen (or CD4) antigen" was considered "the receptor by which the virus gains access to the lymphocyte" (Tedder 1986 p.26-7).
- xii. This white lymphocyte (T-4) has specific proteins on its surface labelled as CD4+ proteins, hence such cells are referred to as T-4 and/or CD4+ Immunologists began to study the 'subpopulations' of white blood cells (called 'lymphocytes') when such cells were thought to possess mutually exclusive functions (Jardinski *et al.* 1976) denoted by their expressed surface markers or glycoproteins (Cantor & Boyce 1977). The latter were thought to act as 'markers' and were called 'differentiation antigens' and given 'cluster differentiation' numbers for sake of nomenclature, known as 'CD' numbers, for example for cluster differentiation antigen number 4 which appears on the outside of the lymphocyte it is written as 'CD4'. These surface molecules are thought to allow antigenic recognition. International workshops are held to exchange the monoclonal antibodies which react with, and thereby define, these CD proteins thus allowing standardization of their nomenclature. Furthermore, subpopulations of lymphocytes/CD markers and their functionality were considered mutually exclusive.
- xiii. This measure, once an immunological research tool for measurement of immunity, today utilized in medical practice as a sign which "announces" (Foucault 1963 trans. 1973 p. 90) the 'diagnosis' ('what is now taking place') of AIDS and hence, anticipates the prognosis ('what will happen'). Thus, this tool has become a 'test' for immunocompetence due to declining numbers of T-cells, "the principal driving force of HIV-1 pathogenesis"

(Wolthers *et al.* 1998 p.44).

- xiv. As a 'surrogate marker', the T-4-cell count constitutes a sign, as it "announces" the history, diagnosis and prognosis (Foucault 1963 trans. 1973). "The sign announces: the prognostic sign, what will happen; the anamnestic sign, what has happened; the diagnostic sign, what is now taking place" p.90 "...it does not offer anything to knowledge; at most it provides a basis for recognition - a recognition that gradually gropes its way into the dimensions of the hidden (p.90)...the sign discloses time...(p. 90-91) "through the invisible, the sign indicates that which is further away, below, later. It concerns the outcome, life and death, time, not that immobile truth, that given, hidden truth that the symptoms restore to their transparency as phenomena (Foucault 1963 trans. 1973 p.91).
- xv. CDC (1992) defines an AIDS diagnosis solely in terms of an HIV positive antibody result and T-4-cell count < 200 per cubic millimetre written as 200mm³.
- xvi. Luc Montagnier stated this himself in a currently aired CNN television advertisement describes himself as the 'discoverer of the AIDS virus' from which I am borrowing.
- xvii. I am using Hanson's definition of a 'test' as a "...representational technique...applied by an agency to an individual with the intention of gathering information" (Hanson 1993 p.19). In terms of Foucault's work the T-4-cell count constitutes an aspect of the 'medical gaze' "not content to observe what was self-evident; it must make it possible to outline chances and risks" (Foucault 1963 trans. 1973 p.89). Thus, the T-cell count becomes in essence, a calculation, and post-identification of HIV, a surrogate, meaning "...something **we hope** will denote the disease" (Horowitz et al 1984 p. 194 emphasis added) meaning HIV/AIDS. An important difference exists between test-givers and test-takers, the former being organizations and institutions administered by professionals who have power over the latter being individuals or groups.
- xviii. In this way it pre-dates and is a precursor of ELISA and Western Blot HIV screening. In 'risk groups' this T4-cell counting established a discourse of "testing" prior to the emergence of the HIV antibody tests allowing stratification of research cohorts. Richard Tedder states this in his account at the Proceedings At the AIDS Conference Newcastle upon Tyne UK 1986 where he states: "AIDS can now be defined as a primary infection of the T-lymphocytes, especially one helper type, by a human retrovirus...in other words it can be diagnosed from the presence of immunodeficiency that results in an increased risk of infection or malignancy. The difference between the two may be subtle **but the broader definition may help us to identify people at high risk and, as we develop therapies to change the progression of the disease, to treat people at an earlier stage of the disease, with more hope of successful intervention.**"(Tedder 1986 p.17) Thus, CD4/T4 became a 'test' of lowered immunity signifier for AIDS/HIV.
- xix. For example: the "switching" between "consumer" and "patient" as the subject and the object (of health services) can be seen in a recent United Kingdom publication (Adam Smith Institute ? date). This document reveals a great deal about the concept and processes of empowerment in relation to discussion of the current 'marketisation' in the UK of health care (Petchey 1989 p.96-97) thus is worthy of attention. Pirie talks about how privatisation was the theme of the 1980s, "one of the most successful policies of all time" which "achieved a major transformation in a few short years" (Pirie, 1991; 4). Pirie describes "privatization", in context of Public Sector Industries, as a **"technique"** which was:**"not chosen as...appropriate to the human services"** ('education and health') where the "technique" has been to **"introduce an internal market on an experimental scale in voluntary areas, with the intention of expanding this over most of the service when its success has been established"** (Pirie, 1991; 3). This internal market will enable resources to be allocated according to the **"choices made by patients"** (also doctors and managers). Thus, the "similar technique" to privatization is revealed as the internal market, applied to the NHS through the process of empowerment ('choices of patients, health care professionals). Thus the internal market is thought of as taking "considerable time..to become consumer-responsive to an acceptable

degree" (Pirie, 1991; 4).

Furthermore, in relation to the switching between subject and object: "a National Health Service patient who has been on a waiting list for treatment should at some point acquire the right to secure the treatment elsewhere at the expense of the local health authority or the appropriate budget holder. If the NHS has taken the money, it should be obliged to provide the treatment. If it fails to do so within a reasonable time, the patient should be **empowered** to secure such treatment elsewhere" (Pirie, 1991; 5, emphasis added). Thus, the Treasury will secure ring-fencing of costs within existing budgets as it will not stand idly by and watch people acquire "rights to demand unlimited expenditure" (Pirie, 1991; 7). The Treasury is seen as being able to achieve this in health by issuing the "health voucher" which patients may acquire, if NHS treatment has not been delivered within a reasonable time frame, to "spend on treatment outside the NHS" (Pirie, 1991; 7). As the "deadline" approaches "health managers would make strenuous efforts to fit in treatment before its deadline. They would devise computer programs to alert them as patients neared the cut-off date, and would scour the country to find empty beds and facilities to secure treatment. One could argue that this is what they should be doing anyway, and that the new **empowerment** rights would make them behave as private sector providers already have to behave. Precisely." (Pirie, 1991; 8, emphases added).

There are similar 'techniques' described by Pirie for application to both the education and local authority sectors.

xx. Quantitative evidence supports this view. For example, as regards the orthodox model of AIDS, the 'orthodoxy' as previously defined, research by the National AIDS Manual (NAM) (a 'mediating structure') demonstrates how pervasive is knowledge of the orthodoxy (see previous definition). In research conducted at the same time as interviews for this study, NAM found great understanding of HIV/AIDS 'orthodox' medicine amongst people with 'AIDS/positive ELISA screen' (NAM 1997 p.18). The results showed that individuals were highly knowledgeable (> 80% scores on some items) about key tenets of therapy based upon the medical model of AIDS, such as the use of Septrin as PCP prophylaxis, the use of PCP prophylaxis for CD4 < 200mm³, the meaning of prophylaxis, the preference for combination of AZT and DDI than AZT monotherapy (NAM 1997 p.18-19). Therefore, more importantly for this paper, it appears that central aspects of the AIDS orthodoxy are known by individuals when asked about experiences of HIV/AIDS. This means that individuals discourse may reflect the 'dominant' (or rather 'circulating discourses'). Also NAM found that over 50% knew about *Continuum* also a mediating structure, which unlike NAM does not receive health authority/pharmaceutical funding and does actively contest the orthodox/retroviral causation theory of AIDS, which NAM does not. However, NAM did not ask respondents if they believed in such therapies only if they knew of them. Their questionnaire was "...difficult to design because a true or false test - with its inevitable risk of confusing people would have been unethical" Thus, their questionnaire was designed in their own words to be "uncontroversial" and has no "...category for 'disagreement' (NAM 1997 p.18) yet "some respondents made it clear they did not agree with some statements" (NAM 1997 p.18) but as such were unreported on by NAM, it is difficult to understand why or how respondents may not have agreed. Thus, it may be argued important perspectives are lost on the basis on "not confusing people" seen as risking being "unethical" (common paternalistic medical torts) if one was to ask people if they actually believed in their therapies or not, which NAM did not undertake.

xxi. I am using frame in a composite sense recalling: "frames of intelligibility that provide it (AIDS) with .. a meager measure of comprehensibility ... are notoriously unstable (Yingling; 1992; 292); and a situation built up in accordance with principles of organisation which governs events and our subjective involvement in them "frame analysis is a slogan to refer to the examination in these terms of the organisation of experience." (Goffman, 1974; 10-11); "Frames impose order on experience - but never arbitrarily or neutral ... (Epstein, 1996 p. 24); "Frames serve as 'accenting devices' that underscore the seriousness of movement claims, they promote the attribution of blame and causality, and they help activists to "align" events and experiences into digestible 'packages'" (Snow and Benford 1988 p.197-217). Also note the conception of the 'decision-frame' (Tversky & Kahneman 1981) for

treatment or a 'frame' of intelligibility which makes AIDS "more comprehensible" (Yingling 1991 p.292). Thus, the T-cell count resemble all of these.

xxiii . Also latterly, grounded within an executive function in relation to a 'long-term survivors' self-help magazine.

xxiii . Mannheim (1952) discussed the 'sociological problem of generations' through discussion of shared psychological and historical events, shaping members of the same generation, and so their own group's influence on history. Lowenberg says a cohort may include "people of all ages even in utero..influenced by a single traumatic event" (Loewneberg 1983 p.247). The name 'cohort' comes from a division of the Roman army and has mostly been used in reference to Nazi youth.

xxiv . Data from my research. ANDREW talks about his experience of being 'in a cohort':"..we're talking very early were talking '81..I was a gay man and I was going every 2 months to the clinic to get tested blood tests and so on ..and em and I suppose by then I had started hearing about what goes on in San Francisco with the ..group of..gay men having funny cancers I think..there was already a name for it which was GRID which was gay related whatever ..so I had swollen glands at the back of my neck ..so while I was in the clinic I asked the doctor there what that meant ..and he said he said well I'll let you see our glands man ..the glands man turned out to be (a doctor) and he mentioned swollen glands meant something that your immune system was defending yourself against something..etc and then he sat down and talked about what was going on in America and..they said they were a little concerned and they were setting up a cohort study..and that they had decided..actually had (been undertaking) research been on people who constitute what were then called a risk category amongst..and I fell into that category ..()they had sex regularly () anyway..he said would I like to come onto it I said yeah yeah what else would it entail what would it entail ..he said it would entail ah ..a full check medical check every three months I said done..I can't get nothing on the NHS normally..that was fine and..that was like the beginning of that very large study they did at the (hospital)." (ANDREW)

xxv . Pinching states: "The best evidence for the type of immunodeficiency in AIDS is the pattern of opportunistic disease seen clinically..However the characteristic immunological profile in laboratory studies confirms that the primary defect is one of cellular immunity" (Pinching 1986 p.41).

xxvi . What has been termed by the Centre for Disease Control USA long ago:"healthy heterosexuals and apparently health homosexual males" (MMWR 1982 May 21; 32: 249-252).

xxviii. Furthermore, this framework of "devotion to technological evidence" constitutes AIDS as currently defined in CDC surveillance criteria, solely as a T-4-cell count of below 200mm³ in the total absence of clinical disease (CDC 1992). Thus, for AIDS monitoring by clinical criteria are considered 'unsatisfactory'. For example, Levacher *et al.* state: "The complexity of the HIV disease process, reflected in the heterogeneity of the clinical course of individual infected patients, makes monitoring solely by clinical criteria unsatisfactory. There is thus a need for biological markers to aid in the monitoring of diseases progression and the response to therapy." (Levacher *et al.* 1992 p.376). This statement recognizes that the clinical experience of AIDS is too varied ("heterogeneity of the clinical course") and forces utilization or recourse to a biological determination in order to define the course of the disease. Thus, such is a biological definition of diagnosis to produce a homogeneity out of a syndrome which is essentially heterogenous in its symptomology.

xxviii. In 1984 Schmidt (1984) postulated a 'group fantasy' origin for AIDS which characterized AIDS as psychogenic phenomenon. This was based on analysis of known epidemics of hysteria which follow the divisions of class, ethnic groups and other cultural differences or 'cultural fault' lines, unlike epidemics of infection which do not display such a feature. Thus, Schmidt proposed that as AIDS, unlike other sexually transmitted diseases, followed specific cultural 'fault lines' represented by the groups most affected: homosexuals and drug addicts which therefore supported a psychogenic aetiology. However, Schmidt correctly interpreted the reduction in cellular and humoral immunity found in AIDS and demonstrated by reduction in T cells as an important factor related to group reactive depression resulting in cell-mediated immunity defect. Schmidt further postulated therapy based upon restoring cell mediated immunity, not unlike many current immunological approaches to AIDS yet what is striking about Schmidt analysis is his insight into group and cultural dynamics, if somewhat overdetermined, and his accurate understanding of the altered immunity in AIDS at this early stage of 1984 (Schmidt 1984 p.23).

xxix. For this discussion I assume psychogenic shock includes 'shock' and 'anticipation' of illness/dying

xxx. Erichsen described shock as symptoms without any causal link, like in the above account where 'reassessment' connects with 'shock', but with no overt causal mechanism (pathogonomic). Erichsen defined shock as an effect "produced by violent injuries from any cause, or from violent emotions" (Young 199 p. 247). The idea of the effect of violence to one part of the body being transmitted to other parts and internal organs, presupposes the existence of some anatomic connection between the other parts, without any postmortem evidence (as shock can occur in the absence of lesions or hemorrhages). The only structure capable of this is the "nervous system, acting upon the great nervous center, the brain ..". Furneaux Jordan argued that fear played a determinative role in some cases of shock. He further describes how this explained why surgical shock is not always proportionate to the severity of the wound inflicted. Such effects work by the linking through the brain to the nervous system, which are also present in fear, an emotion Cannon depathologised by "shifting its traumatic associations to the field of evolutionary biology..redefining it as...a transient state of adaptive arousal". Cannon describes how a survival mechanism, physiological mobilization triggered by fear and anger, can be transformed into its opposite, a pathogenic process called "Voodoo Death". According to Cannon episodes of successful sorcery (or voodoo death) are sequenced: a curse is laid in public, the individual is isolated by his community and then the community converges on the man in "order to subject him to the fateful rite of mourning". The individual is filled with powerless misery and is primed to escape or attack the source of danger but cannot follow either course of action: "If these powerful emotions remain and the body is mobilized for action and if extreme perturbation continues uncontrolled dire results including death can follow" (Cannon 1942 p.76). Cannon postulated a state of sham rage, as the solution to the mystery of voodoo death, as a valid explanation of the nervous shock syndrome reported by Erichsen and Page. Sham rage replicates the states of intense anger and fear, which after several hours is followed by falling blood pressure and cessation of heart beat. Although the "hocus pocus" of voodoo death may appear foreign to our "civilised societies", Cannon mentions how it was seen in cases of World War I soldiers in shock with "wounds ... so trivial that they could not be reasonably regarded as the cause of the shock state" (Cannon 1929).

xxx*i*. The individual so traumatized associates phenomena or stimuli which co-occur with the source of the pain but are incidental to it; such are associated with the shock acquiring a mnemonic power whenever the shock is encountered being forced to remember, re-live its distress and arousal. Over time the scope of the conditioned response is extended through association to objects and other events, but each re-exposure revives the pathogenic memory and the potency of the conditioned stimuli. The ways of responding include phobias, learned helplessness and in the case of posttraumatic stress disorder the seeking out of circumstances to replicate their etiological events, whereby such individuals are "addicted" through endorphin release in the body to memories which originally released these chemicals (Young 1996 p. 245-260).

xxx*i i*. For example other sources report individuals as experiencing 'a shock' or 'shocked' when receiving results in AIDS. Odets describes some responses of gay men judged ELISA negative as "paradoxical" or crisis responses, requiring intervention at a greater rate than those for others judged ELISA positive, in a ratio of 3:1. For example, one client stated: "If anyone deserved it..it is me". Some of these responses embody the same idea in a reverse sense: "...I never thought about being negative, it hadn't even occurred to me. But when the nurse gave me the (negative) results, I was really **shocked**. And for a minute I didn't react, and then the first thing I thought was, "Oh God, what am I going to tell my positive friends?" (Odets 1996 p.45,46). Many other services in AIDS cater for those shocked as a result of testing trauma for example Body Positive Newsletter London UK advertised a 'course' for the recently diagnosed entitled: "Recently diagnosed ? Ready to put the pieces back together again ?" (Body Positive Newsletter 1995 p.3) The caption on the article shows a picture of a dismembered outline human body in black on a shuffled disordered puzzle-tiles, and another showing the correctly set puzzle outlining the black figure put back together.

xxx*i i i*. For example Sande & Volberding (1990): "The hallmark of HIV infection is the progressive depletion of CD4+ lymphocytes. **Presumably** this decrement occurs through direct viral invasion of the cells. (p.186)... rapidly changing T cell pattern in this period (primary HIV infection) and indicate **the need to monitor subjects frequently**. (p.77) ... T-helper cell numbers **alone** provided equally relevant prognostic information. (p.87)..The rate of decline of these cells also has been **cited** as providing prognostic information. (p.87)..The data demonstrating that CD4 number is of **critical prognostic importance** are presented in several studies. (p.87)..The **critical number** of T-helper cells that identify individuals **at risk of developing an AIDS defining event** appears to be 200/mm³ (p.87)..The **rate of decline** of these cells has also been cited as providing diagnostic information. (p.87)..There is some debate about the relative predictive value of absolute CD4 numbers versus CD4/CD8 ratio. However, since absolute CD4 number is currently an important criterion in the prescription of medications such as zidovudine and inhaled pentamidine, the CD4 count should be an essential part of the evaluation of every infected individual. Nevertheless, this measure still has the relative drawbacks.. which make it an imperfect monitoring test" (Sande & Volberding 1990 (p.95-96 emphasis added).

xxx*i v*. Cohen argues that within such a process the role of the community is crucial: if the hexed person resists his fate the community and family withdraws support and the individual is cast out and alone. Death is the only escape from intolerable loneliness and once accepted as an inevitability, the community returns and "act in various ritual ways suggesting death positively" (Cohen, 1988;96). Cohen argues this in context of gay men diagnosed with AIDS and from "professional literature, numerous publications and public media" he developed categories for analyzing the components of the 'hex' and related phenomena in connection with AIDS. This work has been operationalized by the HEAL network in the US.

xxxv. In respect of a normative range in May 1982 the CDC reported: "The normal range of T-lymphocyte helper-to-suppressor ratios established in the CDC laboratory for healthy heterosexual patients is 0.9-3.5 (mean of 2.2). The normal range is being established for **apparently** healthy homosexual males." (MMWR 1982 31:249-252)

emphasis added). However, to date no normal limits have been reported for "apparently healthy homosexual men" by CDC.

xxxvi . In a study on the effects of blood transfusion on patients with *Thalassaemia major* at Cornell University Medical Center and the Sloan Kettering Institute for Cancer Research.

xxxvi i . Patients who have malaria have severe immunoregulatory disturbances including a decrease in their T cells. A significant number of these patients screen ELISA positive but do not develop AIDS, which Volsky et al conclude that "exposure to HTLVIII/LAV(HIV) or the related retrovirus and the occurrence of severe immunoregulatory disturbances may not be sufficient for the induction of AIDS" (Volsky et al, 1986). Canadian researchers have shown how *Mycobacterium tuberculosis* (commonly referred to as TB) as in lepromatous leprosy, an immunosuppressive state frequently develops in the host, characterized by decreased T cells and inverted T4/T8 ratios "**..immunosuppression induced by the infection with *M. tuberculosis* can persist for life, even when TB is not progressive**" (Lamoreaux et al, 1987). These patients did not have high frequencies of KS, PCP or other AIDS indicator diseases.

xxxvi ii . This refines the best prediction of future occurrences allowing "patients to view themselves differently, even if the result reflects no change in their prospective survival. This foreknowledge produces a change in utility" (Asch et al. 1990 p. 48-49).

xxxix . Sande & Volberding (1990) state: "There is some debate about the relative predictive value of absolute CD4 numbers versus CD4/CD8 ratio. However, since absolute CD4 number is currently an important criterion in the prescription of medications such as zidovudine and inhaled pentamidine, the CD4 count should be an essential part of the evaluation of every infected individual. **Nevertheless, this measure still has the relative drawbacks of expense, lack of universal availability, diurnal variability, and interlaboratory variability which make it an imperfect monitoring test. Therefore, insofar as possible, one should perform the test serially in the same laboratory at the same time of the day.**" (Sande & Volberding 1990 p.95-96 emphasis added).

xl . Thus, the technic resembles already-occurring phenomena like those of red-haired or left-handed individuals in a given population. Even though the latter's significance may have cultural interpretations, such are not, in contemporary society at least, utilized for disease monitoring or prescribing medical therapy !

xli . Similarly for the health care professional clinical decision-making is made through the institution of a quantitative framework thus eroding the clinical decision-making based on observation and experience.

xlii . For example, an individual so diagnosed positive on a positive ELISA screen may understand the problematic of AIDS science such to cogently argue as Tony did that their ELISA positive screen is clinically irrelevant. Likewise health care workers may understand also. Yet, in terms of the material/social utility of the diagnosis, how far should scientific belief/understanding be the foundation for agency/action ? Should we ask for welfare payments to be returned unused if the diagnostic label is rejected ? Likewise, should health care workers who do believe in the 'HIV-AIDS hypothesis' be employed in the health services (like Galileo) ? How far should scientific belief become the basis for social consequences ? Even though many scientists, some Nobel laureates, dispute 'HIV-AIDS' hypothesis the point is that social consequences already follow on the basis of scientific belief about 'HIV'. Statutory laws against those judged ELISA positive exist in the US for knowingly having anal/vaginal sexual intercourse without condoms. Such is illegal and imprisonable and similar sanctions are planned for the UK. Globally, many have been imprisoned for less eg. spitting, car accidents where one driver was ELISA positive and later accused of attempted murder for simply bleeding over the other driver etc.

- xliii. See Berger and Neuhaus (1977 p.4). Currently the "empowerment" of service users through the rhetoric of our marketised welfare system appears to entail a similar re-positioning of professional roles. For example a nursing role as traditionally care "giver" becomes in the rhetoric of empowerment, a "facilitator" (Scott 1994;) as one who assists individuals through "participation" in their care. Ramprogus describes how this re-positioning poses an major issue in the professionalisation of nursing (Ramprogus 1995). As a consequence there is a relinquishing of professional authority or power to "patients" through the patient's own validation of their medical diagnosis. Ramprogus says professionalism emphasizes the occupational autonomy of the practitioner without using clients as a reference group for validation of knowledge and skills (Ramprogus 1995 p.53). This is especially the case where the nurse takes on a dual role in becoming both the holder of professional knowledge and the facilitator of self-care. This is viewed as problematic and as embodying a potentially difficult ethical position eg. the nurse as "patient advocate" (Webb 1987).
- xliv. The Universal Dictionary Of The English Language defines allopathic as:"the **ordinary** system of medical treatment which aims at curing disease by remedies having an opposite effect upon the body to that caused by the disease. Name given in contrast to homeopathy" (Universal Dictionary Of The English Language 1958 Eleventh Impression p.27 emphasis added). 'Ordinary' is thus clearly equivalent to 'orthodox' in the medical sense I imply.
- xlv. Another metaphor is "the trace" discussed by cf. Joseph & Winter's analysis of the effects of genetic finger printing:"the epitome of what (our present) culture of traces claims to do". That is to act as a powerful "kind of trace", a trace (or surrogate test) in this analysis for AIDS, which contains within it not only something "unique to that individual", but also in a medical sense an "essence" of that individual (Joseph and Winter 1996 p. 203). As such it represents a way of tracking individuals exemplifying what Joseph & Winter describe as "a new way of organizing society and keeping track of individuals" through "detecting, identifying and organizing identificatory traces" a characteristic of the twentieth century society.
- xlvi. Personal communication. Dr V Turner, Department of Emergency Medicine/University of Western Australia, Royal Perth Hospital, Perth, Western Australia.
- xlvii. For example, Paula Treichler dismisses the "clinical reality" of AIDS as "too complicated" and uninterpretable but for "strategic" purposes (Treichler 1992b).
- lviii. Lupton states:"the current debate around the association of HIV with AIDS" and further mentions the:"The certainty of advice given to the public about risk factors and risk relationships..therefore obscures the continuing, complex, and often very fraught medical and epidemiological debates around the 'truth' of this advice" (Lupton 1995a p.84).
- xlix. Dubious in the sense that PCR (polymerase chain reaction) is again another sensitive screen like ELISA but not specific. It detects "non-infectious viral particles..incapable of going onto infect other cells" (Shenton 1998 p.11) The mathematical model used for the PCR by Wei & Ho (1995) and Ho (1995) has been refuted by Professor of Mathematics, Mark Craddock at the University of Sydney (Craddock 1996) and by Professor Duesberg and the editor of Nature Medicine (Duesberg & Bialy 1995). Yet, the popularity of the PCR screening test is growing.
- l. Like so many things in the 1990s, something 'old' is pre-fixed with the label 'new' and marketed as something novel. King's discourse is based upon that of 'viral load'/PCR. See note 51 for sources which have refuted the mathematical model upon which PCR/viral load is premised. Thus, viral load may be another CD4+/T cell count in the making, an example of what Treichler describes in AIDS as the "construction of what is true or real only in certain specific ways" (Treichler 1987 p.31)

11. Recent calls to implement the randomized control trial (RCT) in British 'HIV-prevention' circles (Oakley *et al.* 1995) contrasts sharply with the reverse call from some AIDS activists and community leaders described in detail by Epstein (1996) for the end of placebo-controlled trials for evaluating experimental AIDS therapies with known and unknown longer term toxicities. It could be asked why such methodological 'rigor' is right in one quarter yet disposable in the other, especially as unproven medications are more potentially harmful than an unproven 'HIV-prevention' project? However, it appears to be the degree of 'rigor' that is at issue as many activists would agree with controls but not placebo controls.

The mobilization for gay rights (Scott 1997) and the drive to make access to the latest (unproven) technology eg. PCR/'viral load' (King 1997) have become inexorably entwined within a complex discursive net which obfuscates clear and rational thinking. Thus, it truly seems "the goal of changing and improving the words and images generated in response to HIV/AIDS has had a higher priority than concrete issues of social and medical policy and the provision of care and services" (Watney 1997 p.77).